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A Phenomenological Study of Faith in Catholic Persons Living with the Diagnosis of Cancer

by

Macrina M. Reyes

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This dissertation is submitted in partial fulfillment of the requirements for the Doctor of Philosophy Degree

School of Health and Medical Sciences

Department of Interprofessional Health Sciences and Health Administration

Seton Hall University

Nutley, NJ

2023

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School of Health and Medical Sciences Department of Interprofessional Health Sciences & Health Administration

APPROVAL FOR SUCCESSFUL DEFENSE

Macrina M. Reyes has successfully defended and made the required modifications to the text of the doctoral dissertation for the Doctor of Philosophy in Health Sciences for the **Summer, 2023**.

DISSERTATION COMMITTEE

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ABSTRACT

Background: There were an estimated 1.9 million new cases of cancer diagnosed in the United States and over 600,000 deaths from cancer in 2022. Cancer is also known as the 2nd most common cause of death behind heart disease in the US. In 2019, there were an estimated 16.9 million cancer survivors in the US. Furthermore, the number of cancer survivors is expected to increase to 22.2 million by 2030. Unfortunately, the persons' spiritual needs are not being addressed or considered by healthcare practitioners as part of the plan of care, especially Catholics. To truly provide person-centered care, healthcare professionals must realize from the onset of the medical intervention that there are more issues to consider than just ordering labs and scans, conducting surgeries, chemotherapy, and radiation.

Purpose: The purpose of this study is to describe how Catholic persons living with the diagnosis of cancer integrate their faith into their healthcare.

Methods: Semi-structured interviews were utilized to collect data, using a qualitative phenomenological approach. The study population was a criterion, purposive sample of Catholic persons with a diagnosis of cancer. Voluntary participants were asked 13 open-ended questions using an Interview Guide Questionnaire that developed on the literature review and the Persona-Centered Care conceptional framework to describe the Catholic person's perspective regarding how faith is integrated into the care of their disease. A Delphi process was for face and content validity of the interview questions. Interviews were transcribed verbatim. Transcripts were coded using in-vivo and descriptive coding then developed into categories for thematic analysis. Interviews were conducted until saturation was achieved and no new codes emerged. Intercoder consensus was obtained.

Results: 11 interviews took place with Catholic persons living with the diagnosis of cancer from

what we know from my current study as compared to other similar studies about faith and

cancer: cancer had a positive impact on faith, faith needs may not be met by Healthcare

providers. lack of Spiritual Chaplaincy and implementation of Person-Centered Care Model is

warranted.

Conclusions: Catholic persons living with the diagnosis of cancer integrated faith into their

healthcare as they believed strongly in God and embraced spiritual coping and personal prayer to

guide their journey. This study supports the Apostolic Letter written by Pope John Paul II in

February 1984 about Salvifici Doloris, which speaks of suffering in general in the light of the

cross and salvific or otherwise known as redemptive suffering by Catholics. Thus, Catholic

cancer persons grew deeper in their faith and understood their reason to life, finding their

purpose in life.

Key Words: Faith, Cancer

 \mathbf{V}

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CHAPTER I

INTRODUCTION

Background

In the United States, an estimated 1.9 million new cases of cancer diagnosed in the United States and over 600,000 deaths from cancer. Cancer is also known as the 2nd most common cause of death behind heart disease in the US (American Cancer Society, 2021). In 2019, there were an estimated 16.9 million cancer survivors in the US. Furthermore, the number of cancer survivors is expected to increase to 22.2 million by 2030. Approximately 40.5% of persons will be diagnosed with cancer at some point during their lifetimes (based on 2017-2019 data). Estimated national expenditures for cancer care in the United States in 2018 were \$150.8 billion. This national expenditure is expected to increase as the population ages and cancer prevalence increases. Costs are also likely to increase as new, and often more expensive treatments are adopted as standards of care (National Cancer Institute, 2020).

As part of a healthcare team coordinating care for oncology patients, I have often observed that intrapersonal needs such as physical, social, mental, emotional, and spiritual concerns of persons with cancer are not considered as part of the care model. Often, healthcare professionals focus solely on the medical care of the person, this can be especially true when first initiating a medical treatment plan. Not surprisingly, all too frequently, the persons 'spiritual needs are not being addressed or considered by healthcare practitioners as part of the plan of care. To truly provide person-centered care healthcare professionals must realize from the onset of the medical intervention that there are more issues to consider than just ordering labs and scans, conducting surgeries, chemotherapy, and radiation.

Patients, especially those with cancer, often discuss how faith, an intrapersonal factor, and/or lack of faith during their medical interventions impacts their wellbeing and care (Swensen, et al., 1993, Sherman et al., 2001, Silvestri et al., 2013). In order to provide true person-centered care, healthcare professionals must better understand the intrapersonal phenomenon of faith in the journey of a person with cancer (Yanez et al., 2009). Understanding the patient's perception on their cancer journey as it relates to their faith as Catholics can enable healthcare professionals to better serve the needs of their patients from a truly person-centered perspective.

Statement of the Problem

Health care in the United States is becoming increasingly person-centered, holistic and wellness focused. Care for the patient's social, emotional and spiritual concerns is imperative to advancing person-centered holistic care. Patients and their families in general want and expect that their religious and spiritual values, beliefs, and practices are considered when designing their plan of care. This is the case too for patients with cancer as it has been noted that nine out of ten patients with cancer signaled a clear wish to discuss their religious beliefs with their oncologists (Norum, 2000). However, very often this goal is not achieved. A potential reason for the absence of patients' religious, spiritual values, beliefs, and practices being considered when designing and delivering person-centered care may result from the lack of evidenced-based knowledge about how to integrate these characteristics into patient care practices (Santana, 2018).

In 2001, The Institute of Medicine defined patient-centered care as "providing care that is respectful of and responsive to individual patient preferences, needs and values and ensuring that patient values guide all clinical decisions." It is where patients actively participate in their medical care with the guidance of their healthcare providers. In the literature, person-centered care (referred to as PCC) as opposed to the term patient-centered care is used to highlight the care of

the whole person, not just their symptoms or disease (Santana et al., 2018). Involving the patient in their care provides personalized, high-quality care and improves the healthcare system's efficiency and effectiveness (Santana, 2018). It asks the question, what matters to you? Instead of the question, what is the matter with you? To practice person-centered healthcare, it is the responsibility of all who directly or indirectly take care of the patient to provide respect for the person's preferences, coordination and continuity of care, emotional support, physical comfort, access to care, and information, communication, and education.

Conceptual Framework

In the review article by Vincensi (2019), Interconnections: Spirituality, Spiritual Care, and Patient-Centered Care, spiritual self-awareness as an important basis for forming one's own spirituality which allows for a higher level of consciousness and knowledge within an intrapersonal relationship was noted. In addition, inter-personal relationships with providers and the environment were also noted to assist in cultivating and increasing self-awareness and knowledge. However, the author expressed that the lack of education and skill, and lack of comfort with spiritual caregiving as major barriers to providing spiritual care. Therefore, the PCC model must put the patient and all their needs at the center of the care plan and provide a system supportive of spirituality and spiritual care interventions.

There are vast interpretations of the term, faith, and the use of spirituality, religion, and faith that it would be prudent to explain the interrelatedness among these three constructs: faith, spirituality and religion. As per Newman, he describes a model whereby spirituality and religion are a function of faith. Both religion and spirituality require faith as a foundation. Faith serves as both the source and the target of their religion or spirituality (Newman, 2004).

Guiding this study proposed exploration is the conceptual framework that integrates the Stages of Religious Faith and Reactions to Terminal Cancer described by Fowler (1981) and the PCC theory (Vincensi, 2019). Fowler (1981) describes faith as an innate human search for meaning, purpose and significance which may evolve in different stages and measures, the stages of religious faith using the stages of faith development which encompasses five questions (Fowler,1981). These questions are:

- 1) Thinking of yourself at present: What gives your life meaning? What makes life worth living for you?
- 2) Can you describe the beliefs and values or attitudes that are most important in guiding your life?
- 3) What is the purpose of human life?
- 4) Is there a "plan" for human lives? Are we individually or as a species determined or affected in our lives by power beyond human control?
- 5) When life seems most discouraging and hopeless, what holds you up or renews your hope?

McCormack & Street (2011) operationalization of the often complicated PCC construct to encompass: exchanging information, fostering healing relationships, recognizing and responding to emotions, managing uncertainty, making decisions, and enabling patient self-management offers a lens to explore the following overarching research question, "How do Catholic persons living with the diagnosis of cancer describe how they integrate their faith into their healthcare?"

Even though the US National Cancer Institute's Strategic Plan for Leading the Nation (2006) call for assessing the delivery of PCC in cancer care, there has been no comprehensive measure of PCC that exists, and stakeholders continue to embrace different conceptualizations and assumptions about how to measure it. Furthermore, implementation of PCC is still unresolved in

many parts of the world. Thus, the purpose of study is to explore the role of faith of Catholic persons living with the diagnosis of cancer in the New York.

Purpose of the Study

The purpose of this study is to describe how Catholic persons with cancer integrate their faith into their lived experience of dealing with the diagnosis of cancer. Using a qualitative phenomenological approach will enable the researcher to gain insight as to the lived experience of Catholic persons living with cancer. Specifically, the researcher seeks to examine the perceived intrapersonal attributes of faith among a group of stage I, II, III, or IV persons with cancer who are undergoing or have undergone chemotherapy, radiation, immunotherapy, surgery or hospice care, who are between 18 to 80 years old, reside in New York, and receive care at Northwell Health Cancer Institute.

It is the belief of Catholics around the world that eternal life is achieved by how we live our life here on earth. Therefore, the significance of this study is that it seeks to understand the person's perception of how they integrate their faith as a Catholic into their cancer journey and thereby provide healthcare professionals with insight as to how the person perceives the impact of their faith and ultimately enable healthcare professionals to better serve the needs from a truly person-centered perspective.

In the literature, several authors have explored faith and its impact on the health of persons living with cancer. However, very few articles exist related to faith and its impact in Catholic cancer patients. In 2015, the National Cancer Institute supported the CRUZA randomized trial which interviewed 348 individuals promoting organizational capacity to implement cancer control

programs across thirty-one Catholic Latino parishes in Massachusetts. The study employed two intervention groups: Capacity Enhancement and Standard Dissemination. Inclusion criteria included Roman Catholic parishes in Massachusetts which offer religious services in Spanish. Results showed that there was limited variability in CFIR (Consolidated Framework for Implementation Research) organizational characteristics in the study population which suggests favorable characteristics for health programming in this group of catholic persons with cancer (Allen, 2020). In addition, the CRUZA study noted a strong reliance on faith, God and parish leaders for health concerns, including use of cancer screening services. As discussed in the Allen, 2016 study, the data also supported the presence of a deep connection between religious beliefs and health. Study participants believed that God and faith are vital for health and healing, and that taking care of the body as the temple of God would in turn allow them to serve God. Participants noted that their reliance on God and faith came in the form of frequent rituals such as prayer to recover from illness and maintain emotional, physical, and spiritual health. They expressed their sharing of miraculous healing through their faith or religious practices. While the CRUZA study employed the implementation of evidence-based cancer control program in a faith-based organization, my study aims to take a deeper dive and further describe the lived experience of Catholic persons living with cancer through the conceptual frame of the person-centered care model combined with the model used by Vincensi, of inter-connectedness of spirituality, spiritual care, and patient centered care. This would add to the body of knowledge looking at the core of the patients' relationship with their God and ways of dealing with death here on earth and preparing for eternal life in heaven, as part of Catholic beliefs. The overall aim of this exploration is to provide insight that can be used to implement initiatives based on evidence-based strategies for faith-based programs in parishes, within the hospital system's chaplaincy department/ patient experience department, and ultimately serve as a foundation to pursue initiatives that would benefit the person-centered care of cancer patients.

Research Questions

Central Research Question

"How do Catholic persons living with the diagnosis of cancer (Stages I-IV) describe how they integrate their faith into their healthcare?

Sub Research Questions

As a Catholic person living with the diagnosis of cancer:

- 1. How have you integrated your faith into your healthcare?
- 2. How would you describe the impact of faith on your healthcare?
- 3. What impact does your faith have on your healthcare?
- 4. How does your healthcare provider TEAM address your faith specific to your healthcare plan?
- 5. What do you believe is the role of your HCP TEAM in managing your diagnosis via the healthcare plan?
- 6. What are your thoughts regarding your HCP TEAMS ability to integrate your faith into your healthcare plan?
- 7. Have you found differences amongst the HCP TEAMS members specific to their ability to integrate your faith into your plan of care? If so, can you elaborate on those.
- 8. What has your experience been with the healthcare system specific to integrating your faith into your plan of care?
- 9. What are your thoughts on how (ways in which) your faith can be integrated into you plan of care to address your cancer management outcomes and beneficial to your well-

being?

10. How has your faith life changed when you were diagnosed with cancer?

11. What challenges, if any, have you had with your faith since you were diagnosed

with cancer?

12. What benefits have you had with your faith since you were diagnosed with cancer?

13. Can you tell me your personal definition of faith?

Terms

Faith

Quoting from the New Testament, Hebrews 11:1, "Faith is the realization of what is hoped for, and the evidence of things not seen." Secondly, as per Gula, faith looks into the deepest dimensions of human experience and sees the presence and action of God. Faith is seeing more than meets the eyes." Thirdly, I will use Fowler's definition of faith: faith is appropriate and intentional participation in the redemptive activity of God (pg. 55, Faith Development and Fowler).

For Christians, faith in God is acceptance of Him and his teaching as revealed in and through Jesus Christ. The Catechism of the Catholic Church defines faith as "man's response to God, who reveals himself and gives himself to man...By faith, man completely submits his intellect and his will to God...it is a free assent to the whole truth that God has revealed...all that which is contained in the word of God, written or handed down, and which the Church proposes for belief as divinely revealed" (26, 143,150, 182).

Simplistically, in faith one will see the invisible and experience beyond the unimaginable.

As per St Thomas Aquinas in his *Summa Theologiae* II-II Q. 2A.1. True faith includes a free will with trust in religious authority—not just accidental agreement with that authority on

other grounds. For Christians, that authority is God's revelation through the Church, whose Sacred Tradition produced Sacred Scripture and guards its orthodox interpretation.

Newmans's Model

Because there are vast interpretations of the term, faith, and the use of spirituality, religion, and faith being used interchangeably, Newman (2004) presented a model for the interrelatedness among these three constructs: faith, spirituality and religion. In Newman's model, spirituality and religion are a function of faith. Both religion and spirituality require faith as a foundation. Faith serves as both the source and the target of their religion or spirituality. Devotion to religion or perception of growth in spirituality may be seen as a measure of greater valence of understanding one's faith.

Further, one can be present without the other. For instance, it is possible for someone to have faith (KNOWING), but not necessarily be religious (DOING). Or someone may have faith and be religious, but not necessarily spiritual (BEING). Moreover, in the strictest sense of the definitions, religion and spirituality are not necessary elements to a person's faith. They are, however, indicators of the depth of faith. Because of the value added to faith due to religion and spirituality, they are often seen as overlapping elements to faith, and though not necessary, are critical to faith growth and development. This model allows the freedom to discuss the three terms interchangeably while giving a context for them. With faith as a foundation, spirituality and religion can

be seen as by-products, those things or ways of life which allow an individual to live out his or her faith. (See Figure 2)

Further, while faith is grounded within an individual, spirituality and religion are

dynamic. They have motion. In other words, there is not a threshold that one can or should attain with either one. Rather, individuals ebb and flow along the "spirituality" and/or "religion" continuums. At certain times in life, one may be more spiritual and perhaps not as religious. At other times, it could be the opposite: one is more religious, yet not as spiritual. However, both essences can feed and assist the other in developing. For instance, acts of religion can assist a person to become more spiritual, and vice versa, acts of spirituality may lead to religiosity. Additionally, the arrows symbolizing "spirituality" and "religion" can take a direction that may plot them to be closer together and heading in the same direction. Or, conversely, the two may be moving in different directions. For instance, one's religious acts may not complement or enhance one's spirituality. Thus, the arrows would be heading in a much wider direction than one whose spirituality and religion both serve to edify the other (Newman, 2004). The simplicity of the model allows one to massage and maneuver those things both tacitly and explicitly that allow one to develop in faith. One can begin to see the distinctiveness, yet interconnectedness of the three terms. Cancer

Cancer, as defined by the American Cancer Society, is a group of diseases characterized by the uncontrolled growth and spread of abnormal cells. If the spread is not controlled, it can result in death. Cancer is caused by external factors, such as tobacco, infectious organisms, and an unhealthy diet, and internal factors, such as inherited genetic mutations, hormones, and immune conditions. These factors may act together or in sequence to cause cancer. Ten or more years often pass between exposure to external factors and detectable cancer. Treatments include surgery, radiation, chemotherapy, hormone therapy, immune therapy, and targeted therapy (drugs that interfere specifically with cancer cell growth).

Cancer Stages

The stage of cancer is based on the extent to which the cancer has spread at the time of diagnosis. According to the American Cancer Society (2007), "cancer's stage is based on the primary tumor's size and location and whether it has spread to other areas of the body." Staging is based on three factors: 1) the size of the primary tumor; 2) absence or presence of regional lymph node involvement; and 3) absence or presence of disease in other organs of the body (American Cancer Society). Once these factors are determined, a disease stage of I, II, III, or IV is assigned for diagnostic purposes, with Stage I representing early stage of disease and Stage IV signifying advanced stage.

CHAPTER 2

REVIEW OF LITERATURE

Historical Background

Patient-centered care, better known as person-centered care, was put forth by the Institute of Medicine (IOM) as one of its objectives for improving health care in the 21st century. Similarly, the 2011 National Quality Strategy (NQS) acknowledged that a person-centered approach would see "a person as a multifaceted individual rather than a carrier of a particular symptom or illness and requires a partnership between provider and the patient with shared power and responsibility in decision making and care management." (U.S. Department of Health and Human Services, 2011) It was identified as an essential foundation for health-care quality and patient safety (Santana et al., 2017). Patient-centered care has been an evolving concept, originally depicted by Edict Balint in 1969 as "understanding the patient as a unique human being" (Balint, 1969).

While no unifying patient-centered care framework/model was found in the literature, a consensus among frameworks and models used in different disciplines supports that three components of patient-centered care are critical to the process. Health promotion, communication, and partnership have been considered across multiple areas of clinical practice as critical to patient-centered care although rarely through empirical studies (Constand, 2014). In agreement with Santana (2018) given that the concept of patient-centered care is evolving, it is important to understand the distinction between patient-centered care and person-centered care (PCC), by which PCC refrains from reducing the person to just their symptoms and/or disease. It calls for a more holistic approach that incorporates the various dimensions to whole well-being, including a person's context and individual expression, preferences and beliefs. PCC is not limited to only the

patient, but also includes families and caregivers who are involved with those who are not living with illness, as well as prevention and promotion activities.

Using the Donabedian health quality improvement model to classify the PCC domains, this framework provides a roadmap to guide the implementation of a PCC model. Structure includes PCC domains related to the health-care system or the context in which care is delivered and provides the foundation for PCC- the necessary materials, health-care resources and organizational characteristics. Process includes domains associated with the interaction between patients and health-care providers. Outcomes show the value of implementing the PCC model, with domains relating to the results from the interaction between the health-care system, health-care providers and patients.

The Conceptual Framework is organized like a roadmap, depicting the practical PCC implementation in the order that should be implemented starting from structural domains that are needed as pre-requisites, to facilitate processes and influence outcome needed to achieve PCC. While PCC was identified as an essential foundation for health-care quality and patient safety in 2001, it has still been a challenge to implement.

Since the purpose of this study is to describe how Catholic persons integrate their faith into their lived experience of dealing with cancer, the Person-Centered Care conceptual framework will be used to describe the patient's perspective regarding how faith is incorporated into the care of their disease. Promoting the use of PCC aims to change our disease-based approach to medicine by providing a comprehensive and holistic person-centered care process that embraces the dignity of human life and welcomes faith as part of the plan of care.

Theoretical Literature

For those who suffer before the end of life may see it as a punishment, a curse, or a struggle; however, Pope John Paul II in his Apostolic Letter, Salvifici doloris states that,

Faith in sharing in the suffering of Christ brings with it the interior certainty that the suffering person "completes what is lacking in Christ's afflictions"; the certainty that in the spiritual dimension of the work of Redemption *he is serving*, like Christ, *the salvation of his brothers and sisters*. Therefore, he is carrying out an irreplaceable service. In the Body of Christ, which is ceaselessly born of the Cross of the Redeemer, it is precisely suffering permeated by the spirit of Christ's sacrifice that *is the irreplaceable mediator and author of the good things* which are indispensable for the world's salvation. It is suffering, more than anything else, which clears the way for the grace which transforms human souls. Suffering, more than anything else, makes present in the history of humanity the powers of the Redemption. In that "cosmic" struggle between the spiritual powers of good and evil, spoken of in the Letter to the Ephesians (89), human sufferings, united to the redemptive suffering of Christ, *constitute a special support for the powers of good*, and open the way to the victory of these salvific powers. (John Paul II, *Salvifici doloris*, 27)

Redemptive Suffering (Salvifici Doloris, Pope John Paul II)

Man, discovering through faith the redemptive suffering of Christ, also discovers in it his own sufferings; he rediscovers them, through faith, enriched with a new content and new meaning. "I have been crucified with Christ, it is no longer I who live, but Christ who lives in me; and the life I now live in the flesh I live by faith in the Son of God, who loved me and gave himself for me (Galatians 2:20)." The Cross of Christ throws salvific light, in a most penetrating way, on man's life and in particular on his suffering. For through faith the Cross reaches man together with the Resurrection: the mystery of the Passion is contained in the Paschal Mystery. The Gospel of suffering signifies not only the presence of suffering in the Gospel, as one of the themes of the Good News, but also the revelation of the salvific power and salvific significance of suffering in Christ's messianic mission and, subsequently, in the mission and vocation of the Church. Faith is sharing in the suffering of Christ brings with it the interior certainty that the suffering person "completes what is lacking in Christ's afflictions;" the certainty that in the spiritual dimension of the work of Redemption he is serving, like Christ, the salvation of his brothers and sisters.

While qualitative studies do not necessarily always propose a theory to guide their exploration, using James Fowler's Theory of Faith Development provides a theoretical foundation acknowledging the seminal work conducted in religious education, pastoral care, and developmental psychology (1981). James W. Fowler III (October 12, 1940 – October 16, 2015) was an American theologian who was Professor of Theology and Human Development at Emory University. He was director of both the Center for Research on Faith and Moral Development and the Center for Ethics until he retired in 2005 (Armstrong, 2020). Fowler identifies Seven Stages of Faith:

Stage 0: Primal Faith; Stage 1: Intuitive-Projective Faith; Stage 2: Mythic-Literal Faith; Stage 3: Synthetic-Conventional Faith; Stage 4: Individuative-Reflective Faith; Stage 5: Conjunctive Faith; Stage 6: Universalizing Faith

Fowler in his writing's further correlates stages of faith and selfhood to what we might call psychosocial "seasons" of life. (pg. 96 from James Fowler's Faith Development and Pastoral Care):

Table 1
Fowler's Faith Stages and Psychosocial "Seasons"

Fowler's Faith Stages	Psychosocial "Seasons"
Stage 0: Primal Faith	Infancy
Stage 1: Intuitive-Projective Faith	Preschool Age
Stage 2: Mythic-Literal Faith	Midchildhood

Stage 3: Synthetic-Conventional Faith	Adolescence
Stage 4: Individuative-Reflective Faith	Young Adulthood
Stage 5: Conjunctive Faith	Middle Adulthood
Stage 6: Universalizing Faith	Middle Adulthood and beyond

Fowler isn't necessarily referring to supernatural faith, but faith in more naturalistic terms- as the innate human search for meaning, purpose and significance which may evolve through discernible stages. However, each stage may not coincide with the chronological age of the individual or his/her personal or social circumstances or that it is an assent to a deeper faith (Swensen,1993). It means that as the individual ages, it does not necessarily mean that faith also becomes deeper in its stages. It is appropriate to note that each developmental stage of faith is descriptive and not prescriptive for the aim is not to prescribe how faith should develop in any individual. However, using this approach of stages of faith with my phenomenological study of cancer patients will aid in the exploration of a person's perception of increased faith correlating with better health outcomes. Even though each person's relationship with God is immeasurable in human terms, their faith, can be as described in Hebrews 11:1, "Faith is the realization of what is hoped for and the evidence of things not seen". Thus, leading me to my research question: How do Catholic persons living with the diagnosis of cancer describe how they integrate their faith into their healthcare?

Empirical Research

The first study to show a marked difference in how patients, their caregivers, and physicians view the influence of faith in medical decision-making noted a clear difference in their view regarding faith. Patients and their caregivers were found to rely heavily on their faith second only to the recommendation of the medical oncologist; whereas physicians felt a patient's faith in God should be the least important factor that patients should consider when deciding therapy (Silvestri et al., 2003).

More recently, Jim et al., (2015) conducted a meta-analysis of religion, spirituality, and physical health in cancer patients and came to several interesting and informative thoughts. First, varying definitions of surrounding religion and spirituality exist in the literature and have likely contributed to heterogeneous measures and in turn, mixed results. Religion is often defined as religious affiliation and service attendance. Spirituality is often defined as a connection to a source larger than oneself and feelings of transcendence). Second, results support that the greater one's R/S the greater the positive association is with better patient-reported physical health. Third, although few spirituality-based interventions have been tested in cancer patients, available findings support that they may improve quality of life and physical recovery.

The National Health Interview Survey found that 69% of cancer patients reported praying for their health, whereas only 45% of the general US population did which may suggest that religion/spirituality can help cancer patients find meaning in their illness and provide comfort in the face of existential fears. Based on Jim (2015) much has been written about the importance of addressing spiritual needs as part of patient-centered cancer care. Nevertheless, studies examining the effects of R/S on health outcomes for cancer patients have reported mixed results, likely in part because of small samples and heterogeneous measures of religion, spirituality, and physical health.

"Faith" in Cancer Persons- Positive Impact

In the literature, several authors have explored faith and its impact on the health of persons with cancer. As depicted in Table 2, there are positive impacts of faith in persons with cancer although religion was not specifically identified. These studies varied from qualitative to mixed methods to quantitative designs. There is a disconnect about acknowledging faith as a source of the treatment plan. Persons with cancer seem to want to talk about it more than healthcare providers.

Table 2
"Faith" in Cancer Persons-Positive Impact

Author/Study Title	Purpose	Design/Methods	Population/Sample	Results/Findings
Swensen,Fuller, Clements/ Stage of Religious Faith and Reactions to Terminal Cancer	To investigate how religious faith affected the way in which people cope w/ terminal cancer, either in themselves or in their spouses.	Mixed Methods Design The stage of religious faith was measured by a scale derived from 5 questions from Fowler (1981)	44 cancer pts and 48 spouses of cancer pts	The problems terminal cancer pts have to cope w/ are different from the problems w/ which their spouses have to cope. Results suggest that impending death impels the cancer pt who has a close relationship to God to focus on that relationship, while the spouse focuses on the immediate problems here on earth with which he or she must cope.
Norum, Risberg, Solberg/ Faith among patients with advanced cancer. A pilot study on patients offered "no more than" palliation	To clarify patients' attitudes to faith	Pilot study Interview	20 pts aged 37-74 yo with incurable cancers	Most pts responded positively to a question about faith. 9 out of 10 pts wished to discuss their religious beliefs with the oncologist.
Feher & Maly/ Coping with breast cancer in later life: the role of religious faith	To identify & examine religious & spiritual coping strategies among elderly women with newly diagnosed breast cancer.	Qualitative Study Structured interview with open-ended questions	Convenience sample of 33 women age 65 yo with breast ca	Religious & spiritual faith provides elderly women newly diagnosed with breast ca with important tools for coping with their illness and should be recognized by diagnosing physicians.

Lissoni et al.,/ A spiritual approach in the treatment of cancer: relation between faith score and response to chemotherapy in advanced non-small cell lung cancer patients	To investigate the influence of spiritual faith on the efficacy of cancer chemotherapy could be mediated by directing the action of chemotherapy on the cytokine network towards promoting antitumor activity.	Quantitative Study	50 metastatic NSCLC pts	Study suggests that spiritual faith may positively influence the efficacy of chemotherapy and the clinical course of neoplastic disease, at least in lung cancer, by improving the lymphocyte-mediated anticancer immune response
Soothill et al.,/ Cancer and faith. Having faith- does it make a difference among patients and their informal carers?	To consider the impact of religious faith on the cancer experience of patients and informal carers.	Questionnaire survey	189 paired patients and carers in England	Having a religious faith does seem to make a difference but it also seems to have a different impact on patients and carers.
Jim, H., Pustejovsky, J., Park, C., et al., (2015). Religion, Spirituality, and Physical Health in Cancer Patients: A Meta-Analysis.	To evaluate R/S and patient-reported physical health	Meta-analysis	2,073 abstracts, 101 samples containing 497 effect-sizes estimates. 32000 adult cancer pts	Results suggest that greater R/S is associated with better patient-reported physical health. May improve quality of life and physical recovery.
Koenig, Larson, & Larson, 2001/Religion and Coping with Serious Medical Illness	To review & discuss role of religion plays in helping pts cope w serious medical illness	Cross-sectional Prospective studies	Pts with serious medical illness	Studies have demonstrated faith in God or a higher spiritual power are common ways of coping with cancer.

"Faith" in Healthcare Providers-Positive Impact

The POSITIVE impact of faith in healthcare providers is shown in Smyre et al., in 2017 who surveyed 1878 physicians and found that 65% of US physicians believe that it is essential to address spiritual concerns at the end of life. (MDs who were more religious were more likely to believe that spiritual life is essential to good medical practice & encourage pt to talk w Chaplain.)

In Silvestri et al., 2003 on the Importance of Faith on Medical Decisions Regarding Cancer Care, in a survey design, quantitative study composed of a convenience sample of 257 medical oncologists, 100 advanced lung cancer pts & their caregivers showed that acknowledgment & respect by doctors of pt's personal beliefs will likely lead to a higher satisfaction with the decision-making process for all involved (Silvestri, 2003).

Table 3
"Faith" in Healthcare Providers-Positive Impact

Author/Study Title	Purpose	Design/Methods	Population/Sample	Results/Findings
Smyre et al., 2017/Physicians' Opinions on Engaging Patients' Religious and Spiritual Concerns: A National Survey	To explore the relative importance of addressing patients' spiritual concerns at the end of life and the appropriateness of interventions in addressing those concerns.	Survey Study	1878 Physicians	65% of US physicians believe that it is essential to address spiritual concerns at the end of life. MDs who were more religious were more likely to believe that spiritual life is essential to good medical practice & encourage pt to talk w Chaplain.
Silvestri et al., 2003/ Importance of Faith on Medical Decisions Regarding Cancer Care	Influence of faith in treatment decisions in cancer pts, their caregivers and physicians	Survey design Quantitative study	Convenience sample of 257medical oncologists, 100 advanced lung ca pts & their caregivers	Largest discrepancy is faith in God. Pts & caregivers ranked it second; whereas, physicians placed it last (p<.0001) *Acknowledgment & respect by MDs of pt's personal beliefs will likely lead to a higher satisfaction w/ the decision-making process for all involved.

"Faith" in Cancer Persons- Mixed Impact

Although I could not find any articles that explored the negative impact of faith in persons with cancer, I found a few articles that spoke about mixed responses. Canada et al., in 2016 examined the impact of cancer on 2309 survivors' religious faith and found that 70% of cancer survivors reported that cancer had a + impact on their religious faith. 17%; relatively rare had a negative impact of cancer on faith was associated with poorer HRQoL, both mental & physical, while + impact of faith was associated with greater mental well-being. Balboni et al., as well found that 88% of 230 advanced cancer patients considered religion to be at least somewhat important.

Table 4
"Faith" in Cancer Persons- Mixed Impact

Author/Study Title	Purpose	Design/Methods	Population/Sample	Results/Findings
Canada, A. et al.,(2016)/Examining the impact of cancer on Survivors' religious faith: A report from the American Cancer Society study of cancer survivors	To explore the + and – impacts of cancer on the religious faith of survivors as well as associations of such impacts w HRQoL	Quantitative study	2309 9-yr cancer survivors of the Amer Cancer Society	70% of cancer survivors reported that cancer had a + impact on their religious faith. 17% relatively rare had negative impact of cancer on faith was associated w poorer HRQoL, both mental & physical, while + impact of faith was assoc
Balboni, T., Vanderwerker, L., Block, S., et al., (2007). Religiousness and Spiritual Support Among Advanced Cancer Patients and Associations With End-of-Life Treatment Preferences and Quality of Life.	To examine factors regarding advanced cancer pts about religiousness	The Coping With Cancer study is a federally funded,multi- institutional investigation	230 advanced cancer pts	88% considered religion to be at least somewhat important. 47% reported that their spiritual needs were minimally or not at all supported by a religious community. 72% reported that their spiritual needs were minimally or not at all supported by the medical system.

"Faith" in Healthcare Providers- Mixed Impact

Yanez et al., investigated whether specific aspects of spirituality function as a resource for cancer survivors and found that achieving meaning & peace appears to be a function consistently as a positive resource for cancer survivors on important dimensions of adjustment, but faith might serve to facilitate or hinder positive adjustment. Using a population from the National Comprehensive Cancer Network, in 2015 Simon found that while a cancer dx can encourage some pts to renew their faith, it can have the opposite effect on others.

Table 5
"Faith" in Healthcare Providers- Mixed Impact

Author/Study Title	Purpose	Design/Methods	Population/Sample	Results/Findings

Yanez et al., (2009)/ Facets of Spirituality as Predictors of Adjustment to Cancer: Relative Contributions of Having Faith and Finding Meaning	To investigate whether specific aspects of spirituality function as a resource for cancer survivors	Longitudinal Design	Study 1- participants were part of the Moving Beyond Cancer (MBC) N-558	Achieving meaning & peace appears to be a function consistently as a positive resource for cancer survivors on important dimensions of adjustment, but faith might serve to facilitate or hinder positive adjustment.
Simon, 2015/Cancer Patents with Strong Religious or Spiritual Beliefs Report Better Health	To evaluate R/S beliefs and health status	Mixed studies	National Comprehensive Cancer Network (NCCN)	While a cancer dx can encourage some pts to renew their faith, it can have the opposite effect on others.

"Faith" in Healthcare Providers- Negative Impact

Though NO specific studies were found on Catholic persons with cancer that had a NEGATIVE IMPACT from the viewpoint of healthcare providers, Powell who was commissioned by NIH did not show that faith slowed cancer growth or improved recovery from acute illness (Kalb, 2003). Columbia University professor Sloan wrote a paper in 1999 attacking faith and healing studies. He did not feel religion has a place in medicine and that directing patients toward spiritual practice can do more harm than good.

Table 6
"Faith" in Healthcare Providers- Negative Impact

Author/Study Title	Purpose	Design/Methods	Population/Sample	Results/Findings
Kalb,2003	To assess faith & health connection	Meta-analysis	Reviewed 150 papers	Study by Powell commissioned by NIH did not show that faith slowed cancer growth or improved recovery from acute illness.
Sloan, 1999/Religion, spirituality, and medicine	Comprehensive review of the empirical evidence & ethical issues			Columbia professor, Sloan felt that directing pts to spiritual practice can do more harm than good.

"Faith" Needs Not Met by Healthcare Providers

Lastly, we see that FAITH needs are not always met by healthcare providers. Spiritual needs of persons with cancer have been found to be **under addressed** by health-care professionals as presented by Cole in 2005, Balboni in 2007, and Jim in 2015.

Table 7

Faith" Needs Not Met by Healthcare Providers

Author/Study Title	Purpose	Design/Methods	Population/Sample	Results/Findings
Silvestri et al.,/ Importance of Faith on Medical Decisions Regarding Cancer Care	Influence of faith in treatment decisions in cancer pts, their caregivers and physicians	Survey design Quantitative study	Convenience sample of 257medical oncologists, 100 advanced lung ca pts & their caregivers	Largest discrepancy is faith in God. Pts & caregivers ranked it second; whereas, physicians placed it last (p<.0001) *Acknowledgment & respect by MDs of pt's personal beliefs will likely lead to a higher satisfaction w/ the decision-making process for all involved.
Astrow et al., 2018/Spiritual Needs and Perception of Quality of Care and Satisfaction with Care in Hematology/Medical Oncology Patients: A Multicultural Assessment	To explore spiritual needs with different cultures	Cross-sectional, observational study	727 cancer pts from Brooklyn, NY	Only 3% reported that a physician had inquired about R/S beliefs and 2.5% had inquired about R/S needs.
Balboni, 2017/ Influence of spirituality and religiousness on outcomes in palliative care patients.	To explore R/S and end of life	Cross-sectional	The Coping with Cancer Study	72% reported that spiritual needs were not supported by the medical team. Most oncology physicians (88%) and nurses (86%) reported that they received no spiritual care training.

Summary of Faith's Impact on Health

The journey to understanding faiths' impact on health has grown from the initial work of Allen et al., (2016) that studied faith in Catholic persons, specifically this CRUZA study noted a strong

reliance on faith, God and parish leaders for health concerns, including use of cancer screening services. In 2020, a book authored by Duquin entitled <u>Fighting Cancer</u>: with the Help of Your <u>Catholic Faith</u> was released. It emphasized that the Gospel indicated that almost every time Jesus healed someone, He said, "Your faith has healed you" or "Your faith has saved you."

By 2020, the American Cancer Society of cancer survivors studied 2309 nine-year survivors of cancer and their impact on religion/spirituality which was measured using items from the Patient-Reported Outcomes Measurement Information System (PROMIS) psychological impact of illness-faith, and HRQoL was measured with the 12-item short form (SF-12). Consistent with the hypotheses, the majority of survivors (70%) reported that cancer had a positive impact on religious faith, while the negative impact of cancer on religious faith was relatively rare (17%).

In summary, faith can be a positive coping strategy, faith can negatively impact care and faith needs are not always met. Looking through the lens of the Catholic persons living with the diagnosis of cancer, researcher would like to explore the intrapersonal faith of the patient, the interpersonal faith of the provider and the faith of the systems/environment in order to evaluate the need for the implementation of a person-centered care model.

Faith in Catholic Cancer Persons

The only study I've found about faith in Catholic Persons with cancer which is by Allen et al., In 2016, the National Cancer Institute supported the CRUZA randomized trial which interviewed 348 individuals promoting organizational capacity to implement cancer control programs across thirty-one Catholic Latino parishes in Massachusetts. The CRUZA study noted a strong reliance on faith, God and parish leaders for health concerns, including use of cancer

screening services. Data also supported the presence of a deep connection between religious belief and health.

While the CRUZA study employed the implementation of evidence-based cancer control program in faith-based organization, my study aims to take a deeper dive and further describe the lived experience of Catholic persons with cancer. The CRUZA randomized trial by Allen, Torres, and Tom et al., In 2016 studied the dissemination of evidence-based cancer control interventions among Catholic faith-based organizations, 31 Catholic parishes were enrolled. 20 were randomized to a "capacity enhancement" intervention and 11 to a "standard dissemination" condition. Manual and Toolkit of materials culturally adapted for (FBOs) Faith-Based Organizations with Latino audiences for five types of (EBS) Evidence Based Strategies recommended by the US Preventive Services Community Guide.

At baseline, only one parish had offered any cancer-related program in the prior year, yet a third had offered some other type of health program of service. At post-intervention follow-up, all parishes offered a greater number of EBS. Findings offer encouraging evidence that packaging and appropriately adapting EBS for cancer control can increase implementation of EBS in Catholic parishes and that even a brief organizational-level intervention to enhance parish capacity could increase the number and variety of EBS activities that can be implemented for cancer control.

CHAPTER III

METHODS

Research Design

Based upon the review of the literature specific to research approaches and designs, the qualitative approach using Interpretative Phenomenological Analysis (IPA) arguably is an appropriate approach to use to explore the voice of the person with cancer-specific to the impact of faith. Interpretative Phenomenological Analysis (IPA) was first introduced by Smith (1998) in the mid-1990s as a phenomenological approach to qualitative research in health psychology. Theoretically, IPA seeks to "explore in detail participants" personal lived experience and how participants make sense of that personal experience" (Smith, 2004, p.40). IPA is a qualitative research approach committed to the examination of how people make sense of their major life experiences and explores experience in a phenomenological sense (Smith, 2009, p.1).

Interpretative Phenomenological Analysis (IPA) is an approach whereby the study of lived experience is emphasized in a qualitative and experiential way. The four leading philosophers in phenomenological philosophy are Husserl, Heidegger, Merleau-Ponty and Sartre. Husserl's work established for us the importance and relevance of a focus on experience and its perception. In developing Husserl's work further, Heidegger, Merleau-Ponty, and Sartre each contribute to a view of the persons and culture, projects and concerns. They move us away from the descriptive commitments and transcendental interests of Husserl, towards a more interpretative and worldly position with a focus on understanding the perspectival directedness of our involvement in the lived world-something which is personal to each of us, but which is a property of our relationships to the world and others, rather than to us as creatures in isolation. (Smith, 2009, p.21). IPA recognizes the central role of the researcher in the analytical and interpretative processes.. IPA has

the capacity for making links between the understandings of research participants and the theoretical frameworks of mainstream psychology.

However, in this dissertation, I employed the phenomenological qualitative approach, a design of inquiry coming from philosophy and psychology in which the researcher describes the lived experiences of individuals about a phenomenon (faith) as described by participants.

Phenomenological research is a design of inquiry coming from philosophy and psychology in which the researcher describes the lived experiences of individuals about a phenomenon as described by participants. This description culminates in the essence of the experiences for several individuals who have all experienced the phenomenon. This design has strong philosophical underpinnings and typically involves conducting interviews (Giorgi, 2009; Moustakas, 1994). Ultimately, the purpose of this phenomenological study was to describe how persons integrate their faith into the lived experience of dealing with cancer.

Sampling: Participants

The sample was drawn from a population of Catholic patients living with cancer ages 18-80 years old who are clinically in stable condition, have normal cognitive function, speak English fluently and live in New York City. Participants were recruited from Northwell Health Cancer Institute who are undergoing or have undergone chemotherapy, radiation, immunotherapy, surgery, or hospice care. The researcher emailed or called contacts using the email or telephone contacts to potential participants from Northwell Health Cancer Institute and ask for leads from other people that fit the criteria. The researcher asked permission to post the email or telephone solicitations from potential participants.

The participants were asked to respond to a brief demographic questionnaire, via email to help the researcher select participants and document the inclusion and exclusion criteria in the study. The participant sampling pool was limited to those participants solicited for this research as defined in this study. An informed consent form, as shown in Appendix B, will be required for each participant prior to participating. The researcher anticipated approximately 8-20 participants for this study or until determined by saturation (Creswell, 2013, Kumar, 2018). A criterion, purposive sampling has proceeded as long as saturation has taken place.

Source of Data

This phenomenological qualitative study used an interviewing method where both the interviewer and the interview questions were the instrumentation used. Memos were used to capture any research thoughts during or after each interview, the interviews were recorded electronically via the Microsoft Teams recording feature. A semi-structured interview method was conducted to gain a deeper understanding of the lived experiences. It was conducted via live one-to-one platform with six feet distancing, virtual platform or telephone interview. The interviews began with open-ended questions formulated as shown in Appendix D. No interview will be conducted without confirming the written and verbal informed consent of the participants. Each participant interview will take place in a single interview session.

Human Participants and IRB Approvals

Participants in this research were asked to read over the consent form that was reviewed and approved by Northwell Health and Seton Hall University's Institutional Review Board. (Appendix C) Participation in this study was completely voluntary and there were no monetary or direct benefits to the participants. There was also minimal risk for participating. Participants were asked to consent to participate in the study and answer questions related to their faith journey as they are living with the diagnosis of cancer in a 30-minute to one-hour interview. Participants

were also informed that the interview would be audio/video-taped, and the data would be confidential and anonymous. Names of participants were not used, and data was coded to protect the identity of all participants.

Data Collection Procedures

Upon receipt of the Confidentiality Agreement from both the Institutional Review Board (IRB) at Seton Hall University and Northwell Health, the study procedures were activated. The researcher emailed individuals via purposive sampling who met the inclusion criteria, using the Email to Potential Participants (Appendix A). Researchers also called potential participants. Potential participants were screened using a demographic survey to be sure they meet the selection criteria. An informed consent form, as shown in Appendix B, was required for each participant prior to participating. After the Catholic cancer patient had received an invitation via email or telephone to participate in a face-to-face in-depth interviews, virtual interview or telephone interview with an average duration of 0.5-1 hour was held at the location of the participant's discretion. Interviews were conducted by researchers using a topic-based interview guide that consisted of open-ended questions related to key elements of the problem. After the interview, the researcher evaluated the topic-based interview guide and checked for any revisions where necessary. All interviews were audio/video recorded and transcribed verbatim via Microsoft TEAMS. In case that there was a technical difficulty, a second audio recorder was available for review. Transcriptions were reviewed for completeness and accuracy by researchers and a peer reviewer as well.

The transcribed interviews were sent to the interviewees for review once. If there was anything to add or delete after reflection, it was discussed. Following the approval of the participant, edits were made as necessary to the transcription, including capturing any reflective thoughts following the

interview. Participants did not take part of the writing or editing as they have no access to any other interview.

Data Analysis

Once transcription was completed, researcher proceeded with coding of transcript after each semi-structured interview allowing time to reflect and edit as needed. As per Charmaz (2001), he describes coding as the "critical link" between data collection and their explanation of meaning. As researchers analyzed the data, the transcribed experiences of participants and their own interpretation of what these experiences mean was thoroughly addressed. Researchers tried to understand her participants 'understanding of their own experiences, making this a double hermeneutic approach. By using the Phenomenological Analysis approach, research aimed to understand the role of faith through the lived experiences of Catholic cancer patients.

A manual overview of transcription was performed prior to the initiation of coding into themes which ensured a deep understanding of the interview process and participant's experience. Guba and Lincoln (1985) recommend constructs of credibility, transferability, dependability, and confirmability, rather than validity and reliability in qualitative studies.

In recapitulation of Chapter III, the outline of the research method was used to answer the research question. A discussion of the procedure, study participants, data collection, and interview questions delineated the details of how this dissertation was conducted. The phenomenological qualitative approach was the methodology used to integrate the lived experiences of having faith in Catholic Cancer patients with their intrapersonal experiences, interpersonal experiences with healthcare providers, and transdisciplinary experiences with healthcare system and/or environment based on the person-centered care model.

CHAPTER 4

RESULTS

In this chapter, I will present the research findings and connect them using a phenomenological approach and provide information in the participant demographics and analysis processes.

Setting

The interviews were conducted over five months between June 22, 2022, through November 21, 2022, and held via Microsoft TEAMS for audio/video recording. All participants were recorded and transcribed; however, one of eleven participants was not able to be transcribed in the recording. Fortunately, the researchers took extensive notes.

The interviews lasted approximately 30 minutes to 60 minutes with an average length of 45 minutes. Interviews were scheduled at the convenience of the participants when they can focus on their responses without interruption.

Characteristics of Participants

The participants included 10 females and 1 male. All live in Staten Island, New York.

All are Catholics. All were in the ages between 48 years old -77 years old.

43% had breast cancer which is consistent with national data as the number#1 type of cancer.

(NCI) Not surprisingly, Breast cancer was the dominant Cancer Type in this study since over 90% of Catholic persons are female. 22% with lymphoma followed by 14% with Ovarian/Endometrial cancer, and 7% each with Multiple Myeloma, Colon, and Thyroid cancer. Of note, five of eleven participants lived in the 10312-zip code which is located near the former Fresh Kills Landfill area which was closed approximately 20 years ago because of intense

community pressure. While previous studies have not shown a correlation to the proximity of this landfill; Staten Island which is xxxx has the highest cancer incidence compared to other boroughs in NYC (NYSDOH,2019).

Table 8

Patient Demographics

Participant's Demographic Info			
Participant #/Age	Cancer Diagnosis	Religion	Address
P1 / 48yo	Left sided Breast	Catholic (semi-practicing)	SI, NY 10312
P2 /6 4yo	Breast	Catholic (practicing)	SI, NY 10314
P3 / 77yo	Hodgkin's Lymphoma	Catholic (practicing)	SI, NY 10301
P4 / 61yo	Breast	Catholic	SI, NY 10302
P5 / 51 yo	Ovarian	Catholic (semi-practicing)	SI, NY 10305
P6 / 76 yo	Multiple Myeloma Thyroid Colon Breast	Catholic (practicing- daily virtual Mass)	SI, NY 10312
P7 / 74yo	Lymphoma Adenocarcinoma GI	Catholic	SI, NY 10312
P8 / 70 yo	Lymphoma	Catholic	SI, NY 10314
P9 / 63 yo	Endometrial	Catholic	SI, NY 10312
P10 / 54yo	Metastatic Breast	Catholic	SI, NY 10312
P11 / 79yo	Breast	Catholic	SI, NY 10314

Data Collection

After obtaining Northwell Health IRB approval to interview Northwell Health Cancer Institute Catholic person the study was initiated. Participants were solicited via email with a

solicitation letter and/or word of mouth. Potential participants were provided with a letter of solicitation that included the email contact of the researcher. I then screened potential participants and confirmed if they met the inclusion criteria to determine eligibility. Then I scheduled Interviews for participants that met the screening criteria and are voluntarily willing to participate in the study, written consent was obtained, and an interview scheduled in MS Teams. Participants who did not meet the criteria were thanked for their time. Interviews were conducted using a web communication platform (Teams) and recorded and transcribed using an Interview Guide. Analysis of the data took place followed by an intercoder agreement consensus.

Thematic Analysis

Data analysis included the review of audio/video recordings conducted via Microsoft Teams, which were transcribed verbatim using the text transcription function in TEAMS and further manually transcribed for accuracy by the PI. To ensure accuracy, all transcripts were reviewed by PI and Committee chair. No information shared by participants was linked to their identity or was used to identify a participant's identity. Participant's identity remained anonymous by assigning codes to all participants (P1, P2, P3, etc) at the start of the interview process. Participants were given an option at the start of the interview to be identified by a pseudonym instead of a participant number code to preserve anonymity. The pseudonym if used were linked to the appropriate participant code number to ensure consistency and accuracy. Any publication or presentations that may evolve from this study will only use the P1, P2, P3 code numbers. Participant's participation in this study resulted in no risks to them personally or to the agency in which they are employed. Participation is voluntary, and participants may leave the

study and discontinue participation at any time. Participants may also decline to answer any question during this interview.

For ease of note taking, getting all the participants input, and not slowing down the interview, I used the audio/video recording function via Microsoft Teams. The recordings made were kept confidential and in a safe place. The investigator transcribing the interview will be the only individuals who have access to the Teams recording. The recording and notes will be kept in a secure location and will be destroyed when the study is complete. Data transcriptions were read and re-read, and participants' names were not located anywhere on the transcriptions, only their code which identified the transcription as P1, P2, P3, etc. The data was coded manually immediately following each interview. PI assigned emergent codes using both in vivo for unique words/language of subjects and descriptive coding to summarize a topic of a passage, both codes work together to bring out the meaning and essence of the data (Creswell, 2013; Saldana, 2016). Coding involved a 2-part process- decoding to determine the core meaning of the passage; and encoding to determine which code to use and label the passage. Categories and themes helped to develop the "voice" of the Catholic persons with cancer who participated in the study. Significant statements, sentences or quotes that provided an understanding of the participant's faith experience living with the diagnosis of cancer were highlighted and grouped into meaning units (Charmaz, 2006; Creswell, 2013; Saldana, 2013; Saldana & Omasta, 2018; Miles et al., 2014). Saturation was achieved when no new codes or themes emerged in participant's voice. Codes were reviewed by faculty researchers for accuracy and to establish consensus reaching intercoder agreement and ensure trustworthiness using an audit trail process (Nowell et al., 2017). To validate the accuracy of the interview, trustworthiness is crucial. Validity and reliability come from trustworthiness of the research. Further, validation of the research emerged

from assessing the "accuracy" of the results (Golafshani, 2003; Seale, 1999; Creswell & Poth, 2013). Once data was reviewed and verified it was represented in figures, tables and/or narrative statements to describe the description of the experience of faith in the Catholic person living with the diagnosis of cancer. No software or databases were used in the process. All data analysis were done manually.

Interview Findings

The first interview question asked the participant, "how have you <u>integrated</u> your faith into your healthcare?" Table 9 provides the actual participation quotes. Based upon these quotes the following categories emerged:

For most of the participants personal prayer played an important role in their faith life. Most articulated that they had a strong belief in God and used that belief to cope with the diagnosis of cancer. Several noted that they had a feeling that they were being guided in the right direction.

Table 9

Interview Question 1

IGQ1. How have you integrated your faith into your healthcare?

SRQ1. How did Catholic persons living with the diagnosis of cancer integrate faith into their healthcare?

- → "I probably have prayed a lot more now than I ever did before. It has not, though changed my way of going to church. I do not actually go to church much, but I still believe. I don't feel that that we have to physically go to church all the time to have faith and belief in God." (P1)
- > "Do whatever you want...I trust you and everything you want me to follow, I will do." (P2)
- > "Faith got me through it." (P3)
- > "I think because of my cancer, I am aware more of my faith and I pray a lot more than usual then." (P4)
- > "I pray a lot since I was in my 20's." "I make my family feel like I'm not a sick person." I have a strong attitude and God listens to me every day even when I am in pain." (P5)
- ➤ "With every next step that we take with this disease, every medication, every person I meet, I pray prior to it. There's nothing that comes without prayer."
 (P6)
- > "Just believe and talk to God that the cancer is gonna go out of your body." (P7)
- > "Just trusting and believing in God and just giving it all to Him." (P8)
- "I just feel that he guides me in the right direction every morning. I'm grateful that I wake up every morning and he's present with me on my mind every day."
 (P(9)
- > "It's always part of me."(P10)
- > "By absolutely surrendering...following my treatment plan...whatever the outcome is." (P11)

- > Prayed a lot more" "I don't feel that *that* we have to physically go to church all the time to have faith and belief in God." (P1)
- > "Left it in God's hands " (P2)
- > "Faith got me through it." (P3)
- > "I am aware more of my faith and I pray a lot more than usual then." (P4)
- > "I pray a lot." (P5)
- > "I pray prior to it. There's nothing that comes without prayer." (P6)
- > "Talk to God" (P7)
- > "Just trusting and believing in God and just giving it all to Him." (P8)
- > "He guides me in the right direction every morning." (P9)
- > "part of me" (P10)
- > "By absolutely surrendering" (P11)

The second interview question asked the participant, "how would you describe the impact of faith on your healthcare?" Table 10 provides the actual participation quotes. Based on the quotes, the following categories emerged: the responses were powerful. They used the impact of faith as their coping skill. They were able to express more empathy and accepted their diagnosis with assurance that their faith will get them through this trial.

Table 10

Interview Question 2

IGQ2. How would you describe the impact of faith on your healthcare?

SRQ2. How do Catholic persons living with the diagnosis of cancer describe the impact of faith on their healthcare?

- > "It gave me strength to get through the treatment, when I was going through the chemotherapy treatment itself. And then now that I'm finished with treatment, I guess when I have down days, it helps me kind of get through a hard day or a bad day or a down day." (P1)
- "It helped me go through every single time I was going to the doctor, chemo. I feel I was in good hands, in God's hand who's helping be going through it all. I was strong!" (P2)
- > "It's half the battle that the belief you will be ok. Cross to bear, get through it...It's your will, not mine. My faith was very strong at all times." (P3)
- > "I encourage my kids and my friends to pray too who may need help." (P4)
- > "Faith gives with strength." (P5)
- > "I don't think I would have made it through cancer 1,2,3 without it. People say oh you're so strong and I have to say no. Believe me, it's not me. But it's you know, it's not my strength, but the whole given from God." (P6)
- > "I have a lot of experience, most of them 90% positive. I became a person with more empathy." (P7)
- > "I pray to not allow me to get ahead of myself...just take things one day at a time to trust in the doctors. Just to me some wisdom and knowledge to be able to not waste the doctor's time to be able to ask the right questions and just again giving it to God." (P8)
- ➤ "I think spiritually it's almost like to me a place where I go for like meditation ...healing...like in my own way." (P9)
- → "It's almost as if I'm not my diagnosis...it allows for me to think that it has to
 be something very powerful that telling it's gonna be alright. Don't look at the
 paper, just look at me, which is God, look at me."(P10)
- > "The impact of faith is believing with faith it's going in the right direction that I was hoping it to be." (P11)

- > It gave me strength to get through the treatment." ((P1)
- > "It helped me go through every single time I was going to the doctor and chemo." (P2)
- > "It's half the battle that the belief you will be ok." (P3)
- > Powerful (P4)
- > "Faith gives me strength." (P5, P6)
- > "I don't think I would have made it through cancer 1,2,3 without it." (P6)
- > "I became a person with more empathy." (P7)
- > "just take things one day at a time to trust in the doctors."(P8)
- > "I think spiritually it's almost like to me a place where I go for like meditation ...healing...like in my own way." (P9)
- > " it allows for me to think that it has to be something very powerful that telling it's gonna be alright." (P10)
- > "The impact of faith is believing with faith it's going in the right direction that I was hoping it to be." (P11)

The third interview question asked the participant, "what impact does your faith have on your healthcare?" Table 11 provides the actual participation quotes. Based upon these quotes, the following categories emerged: no one mentioned that their faith had a negative impact on their healthcare. Most participants expressed a positive impact, while a few said their faith had no impact on their healthcare.

Table 11

Interview Question 3

IGQ3. What impact does your faith have on your healthcare?

SRQ3. What impact does faith have on Catholic persons living with the diagnosis of cancer on their healthcare?

- > "I don't know that it has much impact. That's it. I'm bad." (P1)
- > "It impacted me **greatly.**" (P2)
- > "Have to face, go through it to get better" (P3)
- > "I was scared in the beginning, but after a few months, I was OK. I have to help myself too, and I can see all the support that my family gives me. I'm not afraid in case anything happens to me, I'm not disappointed anymore." (P4)
- ➤ "I don't think without faith, I can fight for myself. It's helping me to pass all the treatment." It's the attitude...it's strength to show how strong I am." (P5)
- > "Because of my faith, I am always looking to God for answers and for help. Because of my belief that God is guiding these doctors to help me." (P6)
- ➣ "I believe that God never, never leave me. Cancer did not take my faith away, only made me a stronger person." (P7)
- ➤ "The simplest way I can explain it is the impact it has is that I give it to God and however things turn out, even if I have to suffer, you know I'm not looking to suffer. But I have to kind of approach it where God just allow me to embrace it and if it is His will that it's not meant to be that you're taking suffering away. Just allow me to embrace it and to unite it with your suffering and we'll get through it together." (P8)
- ➤ "It has a **tremendous impact**!" It's just healing. Not only it's helping me heal physically, it's also helping me heal mentally to dealth with it every day."(P9)
- > "I could have 5 nurses that ar not religious and I don't need them to be because I have enough faith for all of us, but it's nice when you connect that way." (P10)
- > "Go with the flow...I go to Sunday Mass, say my prayers every day, say the rosary and with that practice I know that it's not as if I'm going to be exempted but hope that I will be in the right path." (P11)

- > I don't know that it has much impact." (P1)
- > "It impacted me greatly." (P2)
- > "Have to face it" (P3)
- > "I was scared in the beginning, but after a few months, I was OK." (P4)
- > "I don't think without faith." (P5)
- "Because of my faith, I am always looking to God for answers and for help."
 (P6)
- > "I believe that God never, never leave me." (P7)
- > "The simplest way I can explain it is the impact it has is that I give it to God and however things turn out, even if I have to suffer." (P8)
- > "It has a tremendous impact!" (P9)
- > "I don't need them to be because I have enough faith for all of us." (P10)
- > "I go to Sunday Mass, say my prayers every day, say the rosary" (P11)

The fourth interview question asked the participant, "How does your healthcare provider TEAM address your faith specific to your healthcare plan?" Table 12 provides the actual participation quotes. Based upon these quotes, the following categories emerged: for most of the participants, it was not addressed or slightly addressed. It was disheartening to hear since our spirituality is part of the tenets of Person-Centered Care Model.

Table 12

Interview Question 4

IGQ4. How does your healthcare provider TEAM address your faith specific to your healthcare plan?

SRQ4. How did the healthcare provider team of a Catholic person living with the diagnosis of cancer address faith specific to their healthcare plan?

- > "I don't think it was discussed anything about religion." Except a patient give me a pin once. There wasn't really any talk about faith and religion." (P1)
- > "I don't know how to describe this part. I don't know." (P2)
- > "One doctor specially bonded with me because we have the same beliefs. Didn't get vibes from other healthcare providers." (P3)
- > "The PA encouraged me to pray, made me realize how strong I was. She really looked after me." (P4)
- ➤ "The nurse encourages me. The team treat me real good. I do have a couple nurses which we praying together." (P5)
- > "I don't think they address my faith." (P6)
- > "One nurse asked me my religion. I say I am a Catholic and I say to her, you have to be positive." (P7)
- > "There was this one doctor of mine who was very religious and I'm sure you know who I'm speaking about...occasionally we have conversations about faith, not just treating me with the medications that he was giving me and the treatment protocols that he was offering...But most of my other doctors, we kind of not really get into discussions about faith." (P8)
- > "I don't think other than you." (P9)
- ➤ "never addressed" (P10)
- > "My provider did not really mention anything about faith."
- > "It's my own journey and I believe that it's up to me to integrate it myself."
- ➤ "The protocol is straightforward. They talk about the illness, about the surgery, about the medication." (P11)

- > "I don't think it was discussed anything about religion." (P1)
- > "I don't know." (P2)
- > One doctor specially bonded with me because we have the same beliefs." (P3)
- > "The PA encouraged me to pray, made me realize how strong I was." (P4)
- > "I do have a couple nurses which we praying together." (P5)
- > "I don't think they addressed my faith." (P6)
- > Only one nurse addressed her religion...Seldom addressed (P7)
- ➤ "There was this one doctor of mine who was very religious...we have conversations about faith." (P8)
- > "I don't think other than you." (P9)
- ➤ "never addressed" (P10)
- > "My provider did not really mention anything about faith." (P11)

The fifth interview question asked, the participant, "What do you believe is the role of your HCP TEAM in managing your diagnosis via the healthcare plan? Table 13 provides the actual participation quotes. Based upon these quotes the following categories emerged: some participant responses concentrated on the role of taking care of the physical aspect of the disease, while others felt that it is to provide person-centered care, guided by God and to give hope.

Table 13

Interview Question 5

IGQ5 What do you believe is the role of your HCP TEAM in managing your diagnosis via the healthcare plan?

SRQ5. What did Catholic persons living with the diagnosis of cancer believe is the role of the HCP TEAM in managing their diagnosis via the healthcare plan?

- > "I guess their role is to help me get through the course of treatment, help educate me on what to expect during the course of treatment and also after the treatment." (P1)
- ➤ "They provide a very nice environment for me and for everybody I saw around me." (P2)
- > "Be honest as possible, positive and feeling of caring..not all doctors have ability to make you feel special" (P3)
- > "To give me all the information I needed, all the support." (P4)
- > "They tell me they are praying for me." (P5)
- ➤ "I don't expect them to do anything having to do with my faith or my religion, I just don't expect it. It would be wonderful if they did, and I wish they did, and I wish there was team or a group of people that, you know, we could discuss such things. But in the world that we live in, I just don't expect it." (P6)
- > "He must be patient...understand your situation...and smile at you and ask how you are doing." (P7)
- ➤ "Aware of all my other issues, so they're not just treating me with a tunnel vision approach to something I know. Like, for instance, if I'm seeing an oncologist, I don't expect the oncologist to treat me for another issue. But I would just want him to be aware of the other several issues that are going on with me, especially if he has to administer medicine or describe different treatments and what not. I just want him to be aware!" (P8)
- > "It's healing...the personal touch,...the comfort...the guidance" (P9)
- > "To be hopeful as I was and I am." (P10)
- > "I pray and hope that my healthcare team is guided by God in making the right decision, not making mistakes. I don't mind that they didn't address it because as you know there's a whole bunch of different faiths." (P11)

- > "I guess their role is to help me get through the course of treatment." (P1)
- > "To provide a nice environment" (P2)
- > "Be honest as possible" (P3)
- > "To give me all the information I needed, all the support." (P4)
- > "They tell me they are praying for me." (P5)
- > I don't expect them to do anything having to do with my faith or my religion." (P6)
- > To be patient and understanding (P7)
- ➤ "Aware of all my other issues, so they're not just treating me with a tunnel vision approach to something I know." (P8)
- "It's healing" (P9)
- > "To be hopeful as I was and I am." (P10)
- > "I pray and hope that my healthcare team is guided by God. I don't mind that they didn't address faith." (P11)

The sixth interview question asked the participant, "What are your thoughts regarding your HCP TEAMS ability to integrate your faith into their healthcare plan?" Table 14 provides the actual participation quotes. Based upon these quotes the following categories emerged: in general, the responses provide insight that healthcare provider teams are not well equipped to handle spiritual concerns of patients and; therefore, the ability to integrate faith needs improvement.

Table 14

Interview Question 6

IGQ6. What are your thoughts regarding your HCP TEAMS ability to integrate your faith into their healthcare plan?

SRQ6. What were the thoughts of Catholic persons living with the diagnosis of cancer regarding their HCP TEAMS ability to integrate their faith into their healthcare plan

PARTICIPANT QUOTES

- ➤ "They can definitely integrate my faith into my plan if I was much more religious. I would like them to when it comes to faith." (P1)
- "I'm not telling you because you were there, but it's because I'm telling everybody that I found that such a great people, nurses and everybody. I think just by being so caring...welcoming in the morning and chair is ready. We didn't do any prayer together; however, there was that kind of connection. I don't remember if they offered me to see the spiritual chaplain." (P2)
- > "To be honest, I don't think I experienced it." (P3)
- > "I felt like God put them there for a reason. There were the perfect people to help me."(P4)
- > "They tell me they love me and praying the rosary for me." (P5)
- > "That's an excellent question, haven't given it much thought. By providing people with resources to go to and discuss since the doctor is too busy he barely has enough time." (P6)
- "I don't think so." (P7,P8)
- ➤ "Because I barely have those discussions with people, all my doctors, with the exception of that one doctor." (P8)
 "I think the resources are there, but as far as the ability, I don't think. A 100% it
 - could be stronger."(P9)
- > "The doctors while taking care of me never connected my faith with that."(P10)
- ➤ "That's not really being done at all in my healthcare team, it basically just the progress, follow up the blood work, follow up what's necessary. There is no mention there or anything at all about faith-wise or religion-wise. (P11)

- > "They can definitely integrate my faith into my plan if I was much more religious." (P1)
- > I don't remember if they offered me to see the spiritual chaplain." (P2)
- > "To be honest, I don't think I experienced it."(P3)
- > I felt like God put them there for a reason. (P4)
- > "They tell me they love me and praying the rosary for me." (P5)
- > By providing people with resources to go to and discuss since the doctor is too busy he barely has enough time." (P6)
- > "I don't think so." (P7,P8)
- > "I think the resources are there, but as far as the ability, I don't think." (P9)
- ➤ "The doctors while taking care of me never connected my faith with that." (P10)
- > That's not really being done at all in my healthcare team (P11)

The seventh interview question asked the participant, "Have you found differences amongst the HCP TEAMS members specific to their ability to integrate your faith into your plan of care?" Table 15 provides the actual participation quotes. Based upon these quotes the following categories emerged: for most participants, they found no differences, while others expressed provider dependent.

Table 15

Interview Question 7

IGQ7. Have you found differences amongst the HCP TEAMS members specific to their ability to integrate your faith into your plan of care?

SRQ7. Have Catholic persons living with the diagnosis of cancer found differences amongst the HCP TEAM members specific to their ability to integrate their faith into their plan of care?

- "You actually prayed with me in the beginning and that was really, really nice and I really did appreciate that and still do. It helped me accept and have the strength to kind of deal with the diagnosis end. Christine prayed with me too." (P1)
- > "I didn't see any difference." (P2)
- > "One doctor with same beliefs, attitude-wise. He made me feel special." (P3)
- > "Only in a good way, nothing bad, like they prayed with me, encourage me, You know nothing like that they are putting down my faith or anything. They actually just lift up my faith." (P4)
- > "I see smiles from nurses but accepted differently from those who have faith and those who do not." (P5)
- ➤ "It doesn't. I really do not see differences because I don't." (P6)
- > "In 2008, I remember you are the first person who prayed with me." "When I was very, very down, you took my hand and my daughter's hand and we made a circle and prayed. Since them, I felt very strong. That was it...the beginning...the best medicine!" (P7)
- ➤ "not really...I almost never have those discussions." (P8)
- ➤ "They helped me route my emotions into a spiritual part, instead of going through the whole diagnosis of being angry and disappointed." (P9)
- > "One nurse was entuned with my faith but none of the doctors I had." (P10)
- > "I didn't find any differences at all." (P11)

- > You actually prayed with me in the beginning and that was really, really nice and I really did appreciate that and still do." (P1)
- > "I didn't see any difference." (P2)
- > "One doctor with same beliefs, attitude-wise." (P3)
- > "Only in a good way, nothing bad" (P4)
- > "I see smiles from nurses but accepted differently from those who have faith and those who do not." (P5)
- > "I really do not see differences." (P6)
- > In 2008, I remember you are the first person who prayed with me." (P7)
- > "not really" (P8)
- > "They helped me route my emotions into a spiritual part" (P9)
- > "One nurse was entuned with my faith but none of the doctors I had." (P10)
- > "I didn't find any differences at all." (P11)

The eighth interview question asked the participant, "What has your experience been with the healthcare system specific to integrating your faith into your plan of care?" Table 16 provides the actual participation quotes. Based upon these quotes the following categories emerged: responses varied with no experience or spiritual guidance being given. A priest came to the unit and prayed with all the patients in the room as one participant mentioned which gave her a moment of spiritual assurance that everything will be fine.

Table 16

Interview Question 8

IGQ8. What has your experience been with the healthcare system specific to integrating your faith into your plan of care?

SRQ8. What have Catholic persons living with the diagnosis of cancer experience been with the healthcare system specific to integrating their faith into their plan of care?

- ➤ "The priest came to the unit and prayed with all the patients in the room. That was very touching and I did like that. He prayed for me too even though I was working because I had my cap on my head so and he praying with me at that time too." (P1)
- > "I've had no experience." (P2)
- > "Never addressed, but should be...I don't remember they gave input." (P3)
- > "God intervenes, and hey, you're getting the test!" (P4)
- ➤ "They tell me that they (nurses) pray for me." (P5)
- > "I remember years ago there was a chapel and I was able to go to Mass in the hospital." (P6)
- > "I don't know. I don't think I was asked any questions how to integrate my faith." (P7)
- > "Ohh...I don't feel that the health care system integrated my faith." (P8)
- > "Other than that one person that spiritually touched me constantly, I don't know if it would really." (P9)
- > "No, they were not integrated." (P10)
- > "No, they didn't help me. It's my own belief. It's my own faith and that is what I intend to do." (P11)

- > "The priest came to the unit and prayed with all the patients in the room." (P1)
- > "I've had no experience." (P2)
- > "Never addressed, but should be" (P3)
- > No experience (P4)
- > "They tell me that they (nurses) pray for me." (P5)
- > "I was able to go to Mass in the hospital." (P6)
- > "I don't think I was asked any questions how to integrate my faith." (P7)
- > "I don't feel that the health care system integrated my faith." (P8)
- > "Other than that one person that spiritually touched me constantly" (P9)
- > "No, they were not integrated." (P10)
- > "No, they didn't help me." (P11)

The ninth interview question asked the participant, "What are your thoughts on how (ways in which) your faith can be integrated into your plan of care to address your cancer management outcomes and beneficial to your well-being?" Table 17 provides the actual

participation quotes. Based upon these quotes the following categories emerged:

To have spiritual chaplaincy presence and receiving the Sacrament of Holy Communion gave participants reassurance that they are not alone in this cancer journey which gave them encouragement. Others felt that their personal faith is only for them to deal with and not to be integrated into their plan of care.

Table 17

Interview Question 9

IGQ9. What are your thoughts on how (ways in which) your faith can be integrated into your plan of care to address your cancer management outcomes and beneficial to your well-being?

SRQ9. What are the thoughts of Catholic persons living with the diagnosis of cancer on how (ways in which) faith can be integrated into the plan of care to address the cancer management outcomes and beneficial to their well-being?

- ➤ "The focus was on getting better or getting treatment. I don't believe that there was much talk about faith. If I was more religious, then I believe the healthcare team would have. If they had approach me to see a spiritual chaplain that would actually be a really neat thing." (P1)
- > "My faith is enough for me." (P2)
- ➤ "Never really discussed about it but should have been addressed esp with Spiritual chaplain" (P3)
- > "To have Spiritual Chaplaincy presence" (P4)
- > "By giving support and encouraging me to stay positive..." (P5)
- > "To have an outlet or resource that somebody can go to and speak to." (P6)
- > "One suggestion is to have the priest come when receive infusion...just to say hi, how you feeling, ask if want to have some **Communion.**"(P7)
- > "I don't think that the conversation goes in that direction. It's hard to
 explain...I don't get into those type of personal conversations with my doctors
 because I feel like it's just so private between me and God. I feel like their time
 is so valuable that I don't wanna waste their time or get distracted and then lose
 track of medical questions that I need to ask." (P8)
- > "My faith definitely helped me open my mind...even in worst situations and bad news in general." (P9)
- > "My faith is just mine as if I almost like don't expect anybody else to tell me or do this..."(P10)
- → "It would have been nice to be asked to receive Communion when I
 was hospitalized. If it was offered to me, I will take it."(P11)

- > "If they had approach me to see a spiritual chaplain that would actually be a really neat thing." (P1)
- > "My faith is enough for me." (P2)
- > "Never really discussed about it but should have been addressed esp with Spiritual chaplain" (P3)
- > "To have Spiritual Chaplaincy presence" (P4)
- > "By giving support and encouraging me to stay positive..." (P5)
- > "To have an outlet or resource that somebody can go to and speak to." (P6)
- > "One suggestion is to have the priest come when receive infusion" (P7)
- ➤ I don't get into those type of personal conversations with my doctors because I feel like it's just so private between me and God."(P8)
- > "My faith definitely helped me open my mind..." (P9)
- > "My faith is just mine as if I almost like don't expect anybody else to tell me or do this..."(P10)
- > Search for Communion (P11)

The tenth interview question asked the participant, "how has your faith life changed when you were diagnosed with cancer?" Table 18 provides the actual participation quotes. Based upon these quotes the following categories emerged: for most of the participants, their faith life increased their time to pray providing them with a stronger faith. However, for a few their faith life did not change, not because they had little faith, but because they had a strong faith to begin with.

Table 18

Interview Question 10

IGQ10. How has your faith life changed when you were diagnosed with cancer?

SRQ10. How have Catholic persons living with the diagnosis of cancer faith life changed when diagnosed with cancer?

PARTICIPANT QUOTES

- ➤ My faith life has changed with my diagnosis of cancer by praying a lot more. I accept prayers from anyone and everyone, no matter what denomination. And I pray for others as well. Sometimes I feel guilty because now that I have a problem, now I'm gonna pray and ask for help and all this, but I guess that's human nature, right?" (P1)\
- ➤ "I was more strong. I was praying a little more, which I don't do now, but it's not that I don't do that. It's like I'm becoming a little lazy." (P2)
- > "It didn't change my faith. I'm going to be an example for my grandchildren. Make something positive out of it- to be a good grandmother. It wasn't so hard for me." (P3)
- ➤ "It brought me closer, even my kids. We prayed the rosary together, even with their better halves who are not Catholics." (P4)
- ➤ "Since I have been praying since I was in my 20's, my diagnosis of cancer doesn't change me."(P5)
- > "Now with the diagnosis, I need a closer relationship with God and you know, maybe a wake up call like hey, you know I'm here and you haven't really been praying enough." (P6)
- > "My faith got more stronger." When I went to Church for my first time with cancer, it made me feel very, very, very good...God died for us. He suffered too much. We are to give back. We have to pray. We have to reaffirm our faith. Faith is very, very important." (P7)
- > "My faith just got stronger! Actually, it's never been a situation on oh God, why me? Why did you do this?"(P8)
- ➣ "It became stronger. Feels like there's a presence with me at all times...like in my daily chores and things I do. There's not a moment that I don't think of him. Made me see the world a different way." (P9)
- > "My faith life is the same because I was very strong."(P10)
- > "My faith did not change at all. My faith stays because I maintain what I believe. Well, that is what I saw with my mother. With every situation she handles with prayers and I follow that, also my sisters follow my mother. I just hold on to my rosary with a little pain or whatnot." (P11)

- My faith life has changed with my diagnosis of cancer by praying a lot more."(P1)
- > "I was praying a little more"(P2)
- > "It didn't change my faith."(P3)
- > "It brought me closer, even my kids. We prayed the rosary together." (P4)
- ➤ "Since I have been praying since I was in my 20's, my diagnosis of cancer doesn't change me."(P5)
- > "Now with the diagnosis, I need a closer relationship with God and you know, maybe a wake up call like hey, you know I'm here and you haven't really been praying enough." (P6)
- > "My faith got more stronger."(P7)
- > "My faith just got stronger!"(P8)
- ➣ "It became stronger."(P9)
- ➤ "My faith life is the same because I was very strong."(P10)
- > "My faith did not change at all."(P11)

The eleventh interview question asked the participant, "What <u>challenges</u>, if any, have you had with your faith since you were diagnosed with cancer?" Table 19 provides the actual participation quotes. Based upon these quotes the following categories emerged: surprisingly, most participants suggested that they had no challenges, and accepted with grace their cancer prognosis.

Table 19

Interview Question 11

IGQ11. What <u>challenges</u>, if any, have you had with your faith since you were diagnosed with cancer?

SRQ11. What challenges, if any, have Catholic persons living with the diagnosis of cancer, have had with their faith since they were diagnosed with cancer?

- > "I don't think I've personally had any challenges with my faith." (P1)
- ➤ "My challenge with myself is I have to pray more."(P2)
- > "I haven't had any challenges. Asked to hold my hand and lead the way" (P3)
- > "I don't see challenges, but closer to our faith." (P4)
- > "I ask God to please calm every storm." (P5)
- → "If the answer isn't, you know I have to accept God's answer, right? I have to accept his plan. So that's a challenge because it may not be exactly the way I thought it was going to be. But in the end, He is always right." (P6)
- ➣ "I was angry at first because I dedicated my life's work taking care of patients and now I have cancer. I realized I was thinking the wrong way. If God discerned this for me then I know I must be strong." (P7)
- > "Trying like not to get ahead of myself...like when my wife passed away." (P8)
- > "I think it has brought me to a place where I'm kinder, more thoughtful of other people going through this and I want to help other people." (P9)
- ➤ None (P10)
- ➤ "I really just accepted my diagnosis. I accepted my healthcare team. I thank my healthcare team and trust them through faith." (P11)

- > "I don't think I've personally had any challenges with my faith." (P1)
- > "My challenge with myself is I have to pray more."(P2)
- > "I haven't had any challenges."(P3)
- > "I don't see challenges, but closer to our faith." (P4)
- > "I ask God to please calm every storm." (P5)
- > "If the answer isn't, you know I have to accept God's answer, right? (P6)
- > "I was angry at first because I dedicated my life's work taking care of patients and now I have cancer." (P7)
- > "Trying like not to get ahead of myself...like when my wife passed away." (P8)
- > No challenges (P9,10,11)

The twelveth interview question asked the participant, "What <u>benefits</u> have you had with your faith since you were diagnosed with cancer?" Table 20 provides the actual participation quotes. Based upon these quotes categories emerged: the top three benefits of faith that emerged were a positive attitude, peace, and gratitude.

Table 20

Interview Question 12

IGQ12. What <u>benefits</u> have you had with your faith since you were diagnosed with cancer?

SRQ12. What benefits have Catholic persons living with the diagnosis of cancer have had with their faith since they were diagnosed with cancer?

PARTICIPANT QUOTES

- > "I guess it helped me get through treatment...my little pin St Peregrine." (P1)
- > "I was always very calm.I was very serene."(P2)
- > "I became more sympathetic person, more open, reach out to help somebody."(P3)
- > "I think it made me look at things differently. I've gotten more understanding, more patient, not hot-headed." (P4)
- > "I'm so lucky. I am still awake the next day. I do have a chance to smile and make my coffee and have my breakfast." (P5)
- > "The closeness in my relationship with God has gotten much better." (P6)
- > "I am much stronger that the first cancer and I don't think in my mind that I was sick."(P7)
- > "Basically it was just peace."(P8)
- > "We started to look at people as numbers and not taking them as individually different and what they were going through and it kind of opened my mind to listen more." (P9)
- > "The benefit is that I feel every day that I've been given a miracle."(P10)
- > "The benefit is ...staying put."(P11)

- ➤ "I guess it helped me get through treatment...my little pin St Peregrine." (P1)
- > "I was always very calm. I was very serene."(P2)
- > "I became more sympathetic person, more open, reach out to help somebody."(P3)
- > "I think it made me look at things differently. I've gotten more understanding, more patient, not hot-headed."(P4)
- > "I'm so lucky. I am still awake the next day. I do have a chance to smile and make my coffee and have my breakfast." (P5)
- > "The closeness in my relationship with God has gotten much better."(P6)
- > "I am much stronger that the first cancer and I don't think in my mind that I was sick."(P7)
- > Basically, it was just peace."(P8)
- > "We started to look at people as numbers and not taking them as individually different and what they were going through and it kind of opened my mind to listen more." (P9)
- > "The benefit is that I feel every day that I've been given a miracle."(P10)
- > "The benefit is ...staying put."(P11)

Finally, the thirteenth interview question asked the participant, "Can you tell me your personal definition of faith?" Table 21provides the actual participation quotes. Based upon these quotes the following categories emerged: several definitions emerged from the data with, "Faith is a belief", "an anchor for them" and "To surrender is to hope in the Divine and have full trust in God" beginning the most prominent features throughout.

Table 21

Interview Question 13

IGO13. Can you tell me your personal definition of faith?

SRQ13. What is the definition of faith of a Catholic person living with the diagnosis of cancer?

- > "Faith is believing in someone, an entity" (P1)
- > "To put myself in God's hand." (P2)
- > "Faith to me is somebody watching over me. I feel His presence and holding my hand. I feel deep connected." (P3)
- > "I feel it's what I believe in and what keeps me going." (P4)
- > "Faith is strength." (P5)
- > "It's something that I cannot live without." (P6)
- > "Faith is the best treasure that you have in your life." (P7)
- > "I think faith to me is believing in God naturally and just trusting him in almost every aspect of my life." (P8)
- > "I believe in God and I feel a very spiritual presence and he guides me to have the day." (P9)
- > "It's like clothing that you always have with you." (P10)
- > It's believing in God." (P11)

- > Faith is believing in someone, an entity" (P1)
- > To put myself in God's hand." (P2)
- ➤ "Faith to me is somebody watching over me. I feel His presence and holding my hand. I feel deep connected." (P3)
- > "I feel it's what I believe in and what keeps me going." (P4)
- > "Faith is strength." (P5)
- > "It's something that I cannot live without." (P6)
- > "Faith is the best treasure that you have in your life." (P7)
- > "I think faith to me is believing in God naturally and just trusting him in almost every aspect of my life." (P8)
- > "I believe in God and I feel a very spiritual presence and he guides me to have the day." (P9)
- > "It's like clothing that you always have with you." (P10)
- > It's believing in God." (P11)

Thematic Analysis Associated with Research Questions

When reviewing the categories that emerged from the participants responses to interview guide question 1 which is linked to Sub-Research Question 1 (SRQ1):

How did Catholic persons living with the diagnosis of cancer integrate faith into their

healthcare?

In this study, Catholic persons living with the diagnosis of cancer integrated faith into their healthcare as they believed strongly in God and embraced spiritual coping and personal prayer to guide their journey.

Sub Research Question 2 (SRQ2)

How do Catholic persons living with the diagnosis of cancer describe the impact of faith on their healthcare?

In this study, Catholic persons living with the diagnosis of cancer described the impact of faith into their healthcare as coping skills that afforded acceptance and empathy development.

Sub Research Question 3 (SRQ3)

What impact does faith have on Catholic persons living with the diagnosis of cancer on their healthcare?

In contrary to study by Canada et al., where they examined the impact of cancer on Survivors' religious faith, findings showed 17% had negative impact of cancer on faith was associated with poorer HRQoL. In this study, Catholic persons living with the diagnosis of cancer had mostly a positive impact on their healthcare. However, some did suggest no impact.

Sub Research Question 4 (SRQ4)

How did the healthcare provider team of a Catholic person living with the diagnosis of cancer address faith specific to their healthcare plan?

In this study, Catholic persons living with the diagnosis of cancer felt that their healthcare TEAM did not really address their faith specific to their healthcare, although some individual healthcare providers did address it slightly.

Sub Research Question 5 (SRQ5)

What did Catholic persons living with the diagnosis of cancer believe is the role of the HCP TEAM in managing their diagnosis via the healthcare plan?

In this study, Catholic persons living with the diagnosis of cancer believe that the role of their HCP TEAM in managing their diagnosis via the healthcare plan is to give hope, guided by God in a person-centered care approach specifically taking care of the physical aspect of the disease.

Sub Research Question 6 (SRQ6)

What were the thoughts of Catholic persons living with the diagnosis of cancer regarding their HCP TEAMS ability to integrate their faith into their healthcare plan?

In this study, Catholic persons living with the diagnosis of cancer think that their HCP TEAMS ability to integrate their faith into their healthcare needs improvement. They do not feel that HCP TEAMS are well equipped to handle the spiritual aspect of their health.

Per Balboni et al., 72% reported that spiritual needs were not supported by the medical team. Similarly, Astrow et al., stated that only 3% reported that a physician had inquired about R/S beliefs and 2.5% inquired about R/S needs.

Sub Research Question 7 (SRQ7)

Have Catholic persons living with the diagnosis of cancer found differences amongst the HCP TEAM members specific to their ability to integrate their faith into their plan of care?

In this study, Catholic persons living with the diagnosis of cancer some did not really find differences amongst the HCP TEAMS members specific to their ability to integrate their faith into their plan of care while few others did.

Sub Research Question 8 (SRQ8)

healthcare system specific to integrating their faith into their plan of care?

In this study, Catholic persons living with the diagnosis of cancer experienced some spiritual guidance with the healthcare system specific to integrating their faith into the plan of care by having a priest come for prayers. While others had no notable experiences.

What have Catholic persons living with the diagnosis of cancer experience been with the

Sub Research Question 9 (SRQ9)

What are the thoughts of Catholic persons living with the diagnosis of cancer on how (ways in which) faith can be integrated into the plan of care to address the cancer management outcomes and beneficial to their well-being?

In this study, Catholic persons living with the diagnosis of cancer supported the use of Spiritual Chaplain to have their faith integrated into their plan of care. Those who have strong faith suggested that faith was personal though.

Sub Research Question 10 (SRQ10)

How have Catholic persons living with the diagnosis of cancer faith life changed when diagnosed with cancer? In this study, some Catholic persons living with the diagnosis of cancer believed that their faith life changed when they were diagnosed resulting in an increased prayer life and an overall stronger faith while others said their faith life did not change.

Sub Research Question 11 (SRQ11)

What challenges, if any, have Catholic persons living with the diagnosis of cancer, have had with their faith since they were diagnosed with cancer?

In this study, Catholic persons living with the diagnosis of cancer in general did not identify any challenges with their faith but suggested that they had to be accepting of their prognosis because of their faith. Thus, seek acceptance with grace.

Sub Research Question 12 (SRQ12)

What benefits have Catholic persons living with the diagnosis of cancer have had with their faith since they were diagnosed with cancer?

In this study, Catholic persons living with the diagnosis of cancer believed that their faith benefited them with a positive, peaceful, and grateful attitude.

Sub Research Question 13 (SRQ13)

What is the definition of faith of a Catholic person living with the diagnosis of cancer?

In this study, Catholic persons living with the diagnosis of cancer defined faith as both a belief and an anchor.

Central Research Question

How do Catholic persons living with the diagnosis of cancer (Stages I-IV) describe how they integrate their faith into their healthcare?

In this study, Catholic persons living with the diagnosis of cancer integrated faith into their healthcare as they believed strongly in God and embraced spiritual coping and personal prayer to guide their journey. This study supports the Apostolic Letter written by Pope John Paul II in February 1984 about Salvifici Doloris, which speaks of suffering in general in the light of the cross and salvific or otherwise known as redemptive suffering by Catholics. Lastly, faith is sharing in the suffering of Christ brings with it the interior certainty that the suffering person "completes what is lacking in Christ's afflictions;" the certainty that in the spiritual dimension of the work of Redemption he is serving, like Christ, the salvation of his brothers and

sisters. *Redemptive Suffering (Salvifici Doloris, Pope John Paul II)*. Thus, Catholic cancer persons grew deeper in their faith and understood their reason to life, finding their purpose in life.

CHAPTER 5

DISCUSSION

Based upon the voice of the participants in this study the following 4 insights emerged which can add to the current findings in the literature. (1) Cancer had a positive impact on faith, (2) Faith needs may not be met by healthcare providers. (3) Lack of Spiritual Chaplaincy is acknowledged and (4) Implementation of Person-Centered Care Model is warranted. Due to the growing population of cancer persons living by 2030 to an expected increase of 22.2 million, it is very essential to take a person-centered approach to the whole well-being of the individual person as it pertains to their own spirituality and religiosity. Once's faith is the root of a person's strength to go through the cancer process and it allows them to use their faith as an anchor, a belief that life's struggles are not as hard as if handled alone.

Supportive findings from other studies showed that the majority of cancer survivors (70%) reported a positive impact on religious faith. (American Cancer Society,2020, Jim et al., 2015, Simon, 2015). Although the majority of cancer survivors reported a positive impact on religious faith, Catholic persons living with the diagnosis of cancer in my study did not have any negative impact on them. Patients, especially those with cancer, often discuss how faith, an intrapersonal factor, and/or lack of faith during their medical interventions impact their well-being and care (Swensen, et al., 1993, Sherman et al., 2001, Silvestri et al., 2013). With this supportive evidence in other studies, it shows to promote that person-centered care is essential for the benefit of the person's whole well-being in mind, body and spirit. Systems can help facilitate Spiritual Care by supporting the inter-personal relationships as well as transdisciplinary collaborations of Person-Centered Care models (Vincensi, 2019). Therefore, spiritual chaplaincy programs in hospital settings are beneficial for the care of the whole person, their families and

loved ones. In order to have true person-centered care, healthcare professionals must understand the phenomenon of faith in cancer patients to have better outcomes, quality of life, and patient satisfaction (Yanez et al., 2009). Lastly, healthcare professionals need further training and mentorship to make person-centered care a reality in our present healthcare environment.

Limitations

As with any study, there are limitations. In this study using a qualitative approach with a small sample size generalizability cannot be achieved. However, given that this is one of the first studies seeking to understand the phenomenological qualitative approach was appropriate and since saturation was met, we can feel confident in that we captured the voices of Catholic persons living with the diagnosis of cancer. Again, given that this study employed a Qualitative approach, causality cannot be inferred and should not be, however, future work can expand upon the foundation findings of this work. Additionally, response bias and interview bias are of concern given the study design employed but the researcher took every effort to ensure that bias was checked. An intercoder agreement was obtained.

Suggestions for Future Research

To expand upon the foundation findings of this work, I plan to conduct a quantitative study of people diagnosed with cancer of several faith categories comparing their stages of cancer, diagnosis, age, and whether or not they are practicing their faith. Through the interviews of this study, it was alluded by some of the participants' voice that those who are practicing Catholics had stronger faith as compared to non-practicing Catholic persons. In addition, I would like to build on this work by looking through the lens of the oncology healthcare providers on their perceptions of spiritual care as part of the person-centered care model as well as including a

quantitative arm of the study by creating a survey of their willingness to promote spiritual wellness. Thirdly, I would like to look at the impact of faith on the progression-free survival and overall survival of Cancer persons.

Conclusion

The findings from this study provided a much-needed greater understanding of the lived experiences of Catholic persons on their cancer journey as it relates to their faith.

This understanding will aid healthcare professionals better serve the needs of their patients from a truly person-centered perspective. Ultimately, the findings from this study will enable healthcare researchers, educators, and providers an increased awareness of the spiritual needs of their patients, thereby to serve as a foundation to pursue initiatives that would benefit the person-centered care of cancer persons, especially within the hospital system's chaplaincy department.

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APPENDICES

Appendix A: Letter of Confidentiality Agreement

CONFIDENTIALITY AGREEMENT

This Confidentiality Agreement (the "Agreement"), effective as of the date of the last signature below ("Effective Date"), is entered into by and between Seton Hall University with a business address at Interprofessional Health Science Campus, Building 123, 340 Kingsland Street, Nutley, NJ 07110 ("Site") and The Feinstein Institutes for Medical Research, a New York not-for-profit corporation and 501(c)(3) medical research organization with an address at 350 Community Drive, Manhasset, New York 11030 ("Feinstein"), for itself and its sole member, Northwell Health, Inc. ("Northwell") having an address at 350 Community Drive, Manhasset, NY 11030. Site and Feinstein are each also referred to herein individually as a "Party" and collectively as the "Parties".

WHEREAS, the Parties are interested in collaborating in connection with the performance of a proposed Study, as defined below, by Macrina Reyes, PA, an employee of Northwell ("NW Employee") and student enrolled at Site (the "Purpose");

WHEREAS, pursuant to any such discussions, the Parties may desire to disclose and receive certain Confidential Information relating to the Study;

WHEREAS, Feinstein and Site desire to make such disclosures without conveying any interest or right therein except as expressly set forth herein;

NOW, THEREFORE, in consideration of the mutual covenants and other good and valuable consideration contained herein, the receipt and sufficiency of which are hereby acknowledged, the Parties agree as follows:

- 1. Confid ntial Information. Fernstein, through NW Employee, is conducting a study pursuant to the Protocol entitled "A Phenomenological Study of Faith in Catholic Persons Living with the Diagnosis of Cancer" Northwell IRB application number 22-0329 (the "Study"). The Protocol is incorporated herein by reference. Site, through Michael La Fountaine, EdD, ATC, FACSM, (NW Employee's "Dissertation Advisor"), seeks to evaluate NW Employee's conduct of the Study and dissertation analyzing the results of the Study (the "Evaluation"). As part of the Evaluation, Feinstein may disclose or otherwise make available to Site certain non-public, confidential information, including but not limited to the Study protocol, research subject-level Study data, Study results, draft dissertation manuscripts, and other Study-related documents (collectively, the "Confidential Information"). Confidential Information includes but shall not be limited to unpublished data, observations, methods and materials and any Protected Health Information (as defined by HIPAA), medical records or other patient or research subject information that may be intentionally or unintentionally disclosed to Site. Confidential Information also includes all non-public, confidential information of Feinstein disclosed or made available to Site under this Agreement.
- Exclusions. Confidential Information does not include information that: (a) is or becomes
 publicly available without breach of this Agreement; (b) is shown by written records to have been in
 Site's lawful possession prior to disclosure by Feinstein; (c) is lawfully received by Site from a third party
 without an obligation of confidentiality; or (d) was developed by Site without use, reference to or reliance
 upon the Confidential Information.
- 3. HIPAA. For purposes of the Study and in accordance with the terms of this Agreement and Applicable Law, Institute shall share with or otherwise make available to Site that subset of data collected during the Study that are described in Exhibit A (the "Data Set"). The Data Set may include certain identifiers of the individuals who are the subject of the Protected Health Information (or PH1) (as defined in HIPAA) such as age, cancer diagnosis, religion, postal address information (other than town or city, State, and zip code) and electronic mail addresses; but do not, to Institute's knowledge and belief, contain

any of the following identifiers of such individuals or their relatives, employers or household members; names; telephone numbers; fax numbers; social security numbers; medical record numbers; health plan beneficiary numbers; account numbers; certificate/license numbers; vehicle identifiers and serial numbers, including license plate numbers; device identifiers and serial numbers; Web Universal Resource Locators (URLs); Internet Protocol (IP) address numbers; hiometric identifiers, including finger and voice prints; and full face photographic images and any comparable images.

4. Obligations of Site

- a. Performance of Permitted Activities. Subject to the terms and restrictions hereof, Site shall receive and use and may, as necessary, disclose the Data Set only for purposes of evaluating NW Employee's conduct of the Study in accordance with the Protocol and NW Employee's generation of Study results. These uses are referred to herein as the "Permitted Activities" and shall be performed by Site in compliance with this Agreement, the Protocol, Applicable Law and any and all restrictions contained in the IRB approval and waiver of authorization.
- b. Assurances of Site's Non-Employee Agents or Subcontractors. Site shall not transfer or disclose the Data Set to or share the Data Set with any non-employee agent or subcontractor of Site except with the prior written consent of Institute. Site shall require any agent to whom it provides the Data Set to be bound by the same restrictions and conditions that apply to Site with respect to the Data Set.
- c. Disclosures Required by Law. Site may disclose the Data Set if and then only to the extent that such disclosure is required by Applicable Law, provided that Site notifies Feinstein sufficiently in advance of the disclosure so that Feinstein shall have an opportunity to object to the disclosure on such basis and to seek appropriate relief. If Feinstein objects to such disclosure, Site shall refrain from disclosing the Data Set until Feinstein has exhausted all reasonably available alternatives for relief.
- d. Compliance with Laws; No Commercialization. Site represents and warrants that it will comply with all Applicable Laws with respect to the use and disclosure of the Data Set and in carrying out the Permitted Activities described in the Agreement and, further, that Site will not use or further disclose the Data Set except as permitted or required by this Agreement. Without limiting the generality of the foregoing, Site shall not sell or otherwise commercialize the Data Set.
- e. IRB Review and Approval. Site represents and warrants that it has obtained (or will obtain) IRB review and approval of the Protocol and any other research project giving rise to the use of the Data Set to the extent such IRB review and approval are required by Federal regulations or Feinstein's policies. If, for any reason, the Study is terminated or suspended, or IRB approval of the Study is withdrawn, Site shall immediately notify Feinstein and, unless the Parties otherwise agree in writing, this Agreement may be terminated immediately by Feinstein by providing written notice.
- f. Disclosure to the Minimum Extent Necessary. Site may not seek, use, or disclose more Protected Health Information than the minimum amount necessary to accomplish the permitted purposes described in the Agreement.
- g. Use or Disclosure. Notwithstanding anything in this Agreement to the contrary, Site, whether or not a "covered entity" as that term is defined in HIPAA, may not use or

- 5. <u>Representatives</u>. Site may disclose Confidential Information only to its officers, directors, employees and agents, including Site's Dissertation Advisor (collectively, "<u>Representatives</u>"), who: (a) have a need to know or access the Confidential Information for the Evaluation; (b) are informed or otherwise know of the strictly confidential nature of the Confidential Information; and (c) are subject to confidentiality obligations at least as stringent as those contained herein. Site is responsible for ensuring compliance by its Representatives and will be liable for any use or disclosure of the Confidential Information in violation of the terms of this Agreement by any of its Representatives.
- 6. <u>Required Disclosure</u>. If Site becomes subject to a legal request or order that demands disclosure of any Confidential Information, Site shall promptly notify Feinstein so that a protective order or other

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disclose the Data Set in any manner that would violate the requirements of HIPAA as if Site were a covered entity.

- h. Identification of Individual. Site may not use the Data Set alone or, in the case of Data Set furnished to or accessed by Site in de-identified form, in combination with other materials or data or any other means to identify, to attempt to identify or to contact the individuals who are the contributors or subjects of the Data Set.
- i. Safeguards. Site shall use appropriate safeguards, consistent with prevailing industry best practices, to secure the Data Set against theft and unauthorized access and to prevent use or disclosure of the Data Set other than as provided by this Agreement.
- j. Standards for Electronic PHI. To the extent that Site creates, receives, stores, or transmits electronic PHI, Site shall also implement administrative, physical and technical safeguards that reasonably and appropriately protect the confidentiality, integrity and availability of any electronic PHI that may be transmitted in conformity with the requirements of HIPAA or any other applicable Federal or state laws.
- k. Reporting. Site shall report to Feinstein within twenty-four (24) hours of Site becoming aware of any use, theft or disclosure of (or unauthorized access to) the Data Set in violation of this Agreement or Applicable Law, including, without limitation any disclosure of PHI to an unauthorized subcontractor. To the extent that Site creates, receives, stores, or transmits electronic PHI, Site shall appropriately report to Feinstein any "security incident", as that term is defined by HIPAA or other applicable Federal or state laws. Site recognizes that Site is not the agent of Feinstein and Feinstein is not responsible for any breach or other misuse of the Data Set by Site. Additionally, if Site is a "covered entity" as that term is defined in HIPAA, Site will comply with the breach notification requirements applicable to covered entities in HITECH and the Privacy Rule, and will report any "breach", as that term is defined in HITECH and the Privacy Rule, to the appropriate individuals, organizations and agencies as required by and in accordance with the law. Site will notify Feinstein before it makes any report to a third party regarding any breach or violation of this Agreement and Feinstein will have the right to review and comment on any such report.
- Mitigation of Security Incident or Breach. Site shall mitigate promptly, to the extent practicable, any harmful effect that is known to Site caused by a security incident regarding electronic PHI or breach of unsecured PHI by Site in violation of this Agreement, HIPAA, or other applicable Federal or state laws.

appropriate relief or remedy may be sought. Only that portion of Confidential Information that is I required to be disclosed may be disclosed hereunder.

- 7. <u>Return or Destruction.</u> Within five (5) days of request by Feinstein, Site shall return or d (and certify as to the destruction) all Confidential Information, including any copies th Notwithstanding the preceding sentence, Site may retain one secure archive copy of the Confidential Information to monitor its ongoing obligations bereunder, provided that any such retained copy continue to be subject to the confidentiality and non-use obligations set forth in this Agreement.
- 8. <u>Term.</u> The term of this Agreement is for a period of one (1) year from the Effective Date. Party may terminate this Agreement with immediate effect at any time, with or without cause, giving written notice to the other Party; provided, however, that Sie's obligations hereunder shall r in effect during the term of this Agreement and for a period of five (5) years following the earl expiration or termination of this Agreement. Notwithstanding the foregoing, Sie's no confidentiality, and nondisclosure obligations regarding PHI provided or obtained under this Agre shall not lapse. Notice to a Party shall be sent to that Party at the address set forth in the Preamble.
- 9. <u>Equitable Relief.</u> Site acknowledges that an actual or threatened breach of this Agreement result in irreparable damage and injury. Site agrees that, in addition to any other available rights remedies, Feinstein shall be entitled to an injunction restricting Site from committing or continuing violation of this Agreement in a court of competent jurisdiction.
- No Re resentations or Warranties. The Confidential Information is provided on an as-is basis, without warranties of any kind, either express or implied.
- 11. No Transfer. Site shall acquire no rights in or to the Confidential Information other than the limited right to access and use the Confidential Information for the Evaluation as described in this Agreement. All right, title and interest in and to all Confidential Information shall remain with Feinstein.
- 12. <u>Governing Law.</u> This Agreement shall be governed by the laws of the State of New York. The Parties agree to submit to the jurisdiction of the courts of the State of New York for the purpose of interpreting or enforcing any of the provisions of this Agreement.
- 13. No Publicity. The Parties shall maintain as confidential this Agreement, the fact that discussions are taking place between the Parties and the content of such discussions, and shall not issue or make, or cause to be issued or made, any announcement or any other public disclosure concerning this Agreement or any discussions between the Parties.
- 14. <u>Miscellaneous.</u> This Agreement constitutes the entire agreement between the Parties with respect to the subject matter hereof and supersedes all prior representations, agreements and understandings, written or oral. This Agreement may not be modified except by written instrument signed by the duly authorized representatives of both Parties. If any provision, or portion thereof, of this Agreement is or becomes invalid under any applicable statute, rule of law or court order, it is to be deemed stricken and the rest of the Agreement shall remain in full force and effect. This Agreement may be executed by facsimile or electronic means (including .PDF or electronic document signature software) and in counterparts, each of which shall be deemed an original and all of which taken together shall be deemed to constitute one and the same agreement.

IN WITNESS WHEREOF, the Parties have executed this Agreement as of the Effective Date.

Seton Hall University

Name: John Buschna

Title: Tentura Assoc Prevent

Date: 6/6/2

The Feinstein Institutes for Medical Research

By: Dare

Name: Diane C. Quinn

Title: AVP, Financial Operations

Date: 6/2/2022

Appendix B: Informed Consent Form

May 15, 2021

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Dear	•	
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My name is Macrina Reyes, PA and I am a doctoral student at Seton Hall University in the Department of Interpersonal Health Sciences and Health Administration. I am conducting a research study in partial fulfillment of my dissertation requirement for the PhD in Health Professions Leadership degree on "The Phenomenological Study of Faith in Catholic Persons Living with the Diagnosis of Cancer."

The purpose of the study is to describe how persons living with the diagnosis of cancer (Stages I-IV) integrate their faith into their healthcare. By addressing the root of the problem from the patient's perspective of their own faith and how that intrapersonal faith translates to their relationship with their healthcare providers and the healthcare system and environment, I would hope that that it would add to the body of knowledge to be able to implement person-centered care strategies that would lead to be evidence-based and be part of standard of care.

Furthermore, I would hope that ones 'life here on earth would be better prepared to share eternal joy in heaven with God, even those who are not Catholics, may find this beneficial for themselves.

If you are interested in participating in this study, please email me at macrina.reyes@student.shu.edu or contact me at cell# (917) 538-5044.

To maintain confidentiality, no personal identifying information will be collected during the

semi-structured interview lasting 45-60 minutes and all data will be reported to reflect the

population as a whole. If you do wish to participate, you will have the opportunity to obtain a

token of appreciation for your time and effort.

If you have any questions concerning this study or your rights as a study participant, please

contact me, the primary investigator, at my email above.

Thank you for your time and consideration.

Blessings,

Macrina M. Reyes, PA-C, MS

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Appendix C: Exempt Approval Letter (page 1)



Institutional Review Board FWA #00002505

Office of the Human Research Protection Program
125 Community Drive
Great Neck, NY 11021

Phone: 516-465-1910

The study cannot begin enrollment until you receive <u>Northwell Institutional</u>

<u>Approval</u> (IA). Institutional Approval is separate from IRB approval, and will be issued in a separate letter. For IA guidance click <u>here</u>, or visit the HRPP website.

To: Macrina Reyes

From: Hallie Kassan, MS, CIP

Director, Human Research Protection Program

Date: June 20, 2022

RE: IRB#: 22-0329

Protocol Title: A Phenomenological Study of Faith in Catholic Persons Living

with the Diagnosis of Cancer

Dear Macrina Reyes:

The above referenced project meets the criteria outlined in 45 CFR 46.101 for EXEMPTION. The following category applies to the project:

45 CFR 46.104 (d) (2)(iii) Research that only includes interactions involving educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures, or observation of public behavior (including visual or auditory recording) where the information obtained is recorded by the investigator in such a manner that the identity of the human subjects can readily be ascertained, directly or through identifiers linked to the subjects, and an IRB conducts a limited IRB review to make the determination required by Sec. 46.111(a)(7).

The following people are approved to participate in this study: Macrina Reyes

You have been issued a waiver of documentation of authorization as per 45 CFR 164.512 for the use and disclosure of information for research purposes.

Appendix C. Exempt Approval Letter (page 2)

It is your responsibility to notify the IRB in writing of any changes or modifications made in the research study design, procedures, etc. which do not fall within one of the exempt categories. Such changes necessitate a new, complete IRB submission. If the IRB receives no correspondence on this study for three years, the file will be closed.

The Institutional Review Board will be notified of this action at a meeting.

Investigators are reminded that research must be conducted in accordance with all applicable Department of Health and Human Services regulations 45 CFR 46, Food and Drug Administration regulations 21CFR 50, 21CFR 56,21 CFR 312, 21 CFR 812, and the Health Insurance Portability and Accountability Act (HIPAA).

All studies are subject to audits by the Office of Research Compliance and/or Institutional Review Board to confirm adherence to institutional, state, and federal regulations governing research.

NOTE: This approval is subject to recall if at any time the conditions and requirements as specified in the IRB Policies and Procedures are not followed (see next page and web site: https://feinstein.northwell.edu/sites/northwell.edu/files/2020-12/HRPP-Policies-and-Procedures.pdf)

NOTE: All IRB Policies and Procedures must be followed, including the following:

- 1. Using only IRB-approved consent forms, questionnaires, letters, advertisements, etc. in your research.
- 2. Submitting any modifications made to the study for IRB review prior to the initiation of changes except when necessary, to eliminate apparent, immediate hazards to the subject.
- 3. Reporting unanticipated problems involving risk to subjects or others.
- 4. Prior to implementation, any changes made to studies utilizing TAP must have COPP, as well as IRB approval.

Appendix D: Interview Guide Questions

INTERVIEW GUIDE

- IGQ1. How have you integrated your faith into your healthcare?
- IGQ2. How would you describe the impact of faith on your healthcare?
- IGQ3. What impact does your faith have on your healthcare?
- IGQ4. How does your healthcare provider TEAM address your faith specific to your healthcare plan?
- IGQ5. What do you believe is the role of your HCP TEAM in managing your diagnosis via the healthcare plan?
- IGQ6. What are your thoughts regarding your HCP TEAMS ability to integrate your faith into your healthcare plan?
- IGQ7. Have you found differences amongst the HCP TEAMS members specific to their ability to integrate your faith into your plan of care? If so, can you elaborate on those.
- IGQ8. What has your experience been with the healthcare system specific to integrating your faith into your plan of care?
- IGQ9. What are your thoughts on how (ways in which) your faith can be integrated into you plan of care to address your cancer management outcomes and beneficial to your well-being?
- IGQ10. How has your faith life changed when you were diagnosed with cancer?
- IGQ11. What challenges, if any, have you had with your faith since you were diagnosed with cancer?
- IGQ12. What benefits have you had with your faith since you were diagnosed with cancer?
- IGQ13. Can you tell me your personal definition of FAITH?