Reconsidering Quality End-of-Life Care Standards for Women with Metastatic Breast Cancer Utilizing the Patient and Family Experience

by

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Background: It is estimated that nearly one third of the 3.5 million women in the United States with a history of breast cancer will develop metastatic disease. The median survival time for metastatic breast cancer (MBC) is between 24-52 months, with only 20% surviving 5 years or more (Laohavinij et al., 2017; Mariotto et al., 2017a; Miller et al., 2016; Santa-Maria & Gradishar, 2015). This variability in survival time and treatment course can be attributed to an array of factors such as MBC disease subtypes, socioeconomic influences, provider differences, and patient and family preferences (Andre et al., 2004; Cleeland et al., 2014; Goldhirsch et al., 2011; Lobbezoo et al., 2013; Mosher et al., 2013; Reed et al., 2012; Sotiriou et al., 2003; Sperduto et al., 2012). Disease heterogeneity results in multiple therapeutic options prescribed sequentially through a progressive, life ending course of illness. Aggressive therapy until the end-of-life (EOL) is the new treatment paradigm for many metastatic cancers. Because some therapies do prolong life, it can be challenging for clinicians and patients to know when sequential treatments for progressive cancers, and specifically MBC, becomes futile and poses a risk for poor quality of EOL care for patients and a poor death experience for their families (Andre et al., 2004; Cleeland et al., 2014; Haun et al., 2017; Mosher et al., 2013; Park et al., 2018; Reed et al., 2012; Sorensen et al., 2012). While quality standards are established for EOL care, it is not clear that these standards are in accordance with the expectations or wishes of patients and families accustomed to this new highly aggressive treatment paradigm (Earle et al., 2003; Emanuel & Emanuel, 1998; Ferrell et al., 2017).

Purpose: The purpose of this study will be to comprehensively assess the current quality of EOL care in women diagnosed with and deceased from MBC.

Specific Aims: The proposed study will examine EOL care through four specific aims:

1) Perform a retrospective chart review of demographic, social, patient health, clinical, supportive care, social work, advance directives, goals of care discussions, and EOL care indicators of deceased MBC patients to assess for EOL quality care;

2) For women deceased from MBC, determine the designated personal representative's (DPR) assessment of the quality of EOL care and death experience via the Quality of Death and Dying Questionnaire (QODD);

3) Explore the DPRs own, and their perception of the patients, view of EOL care and death quality through a qualitative telephone interview; and

4) Integrate the findings from Aims 1,2, and 3 in order to present to key stakeholders a comprehensive description of 1) current MBC EOL care quality and 2) a suggested protocol and implementation plan for best practices to achieve optimal EOL quality. The final protocol will also consider any key stakeholders feedback received.

Methods

Specific Aim 1 – Through a protocolized and verified chart review, assess *demographic factors* (age at MBC diagnosis, age at death, race, sex), *social factors* (spiritual affiliation, neighborhood deprivation score derived from zip code, and marital, employment, and insurance status), *patient health factors* (mental health comorbidities, physical comorbidities), *clinical factors* (tumor type: estrogen receptor (ER+/-) and/or Human Epidermal Growth Factor Receptor 2 (HER2) status, length of survival), *supportive care factors* (palliative care [presence], social work [presence],

advance directives [presence], and goals of care discussions [if occurred, length of time prior to death, times occurred], and *EOL care indicators* (hospice care [presence, length of time], place of death, Intensive Care Unit (ICU) admission 30 days or less prior to death, new chemotherapy in the last 30 days of life, any chemotherapy in the last 14 days of life, more than one Emergency Room (ER) visit in the last 30 days of life, and more than one hospital admission in the last 30 days of life) of MBC patients. Through descriptive, comparative, and correlative statistics, this aim will provide predictor variables for patients at risk for poor life quality at the EOL and death experience.

Specific Aim 2 – The perceived quality of the death experience for women deceased from MBC, through the perception of the DPR, will be described. The cohort will be recruited from a large university healthcare system in southwest Pennsylvania, a local Pittsburgh cancer care support group, and nationwide social media platforms with an MBC emphasis. The QODD questionnaire on a Qualtrics platform will be utilized. Descriptive, comparative, and correlative statistics will be utilized for analysis.

Specific Aim 3 – Using a mixed method design at the survey completion; participants will then indicate their willingness to join in a telephone interview. Using NVivo12 software, content from the interviews will be coded per content analysis by the PI, an expert clinical nurse (*NVivo Qualitative Data Analysis Software*, 2020). Common themes will be identified and recorded in the respondent's own words. Using constant comparative techniques, codes will then be clustered into themes, and themes will be clustered into categories (Boeije, 2002). A second coder will analyze for agreement and added reliability to confirm established codes.

Specific Aim 4 – Integrate the findings of Aims 1, 2, and 3 in order to present to key stakeholders a comprehensive description of 1) current MBC EOL care quality, and 2) a

suggested protocol and an implementation plan for best practices to achieve optimal EOL quality. The final protocol will also consider key stakeholders feedback received.

Though the integration of Aims 1, 2, and 3, this will achieve a comprehensive description and protocol for quality in EOL care and death experience for MBC patients. In addition, the stakeholders will be asked for their reaction and evaluation of the implementation plan. The data will first be analyzed according to each of the collected methods. Using an explanatory sequential design, the qualitative data will provide additional context for the quantitative data collected through the QODD survey (Wisdom & Creswell, 2013).

Results

Specific Aim 1 – A total of 167 women were included in the retrospective chart review analysis. The majority of the sample, (n=132, 79%), were under the age of 65 years at the time of diagnosis. Most women were White, reported a spiritual affiliation, and were either married or partnered. All were insured, with a majority being publicly insured through Medicare or a Pennsylvania-based program for coverage of breast cancer diagnosis and treatment (n=119, 84.4%). Over 25% of the MBC cohort had one or more mental health comorbidities and over 50% of the MBC cohort had one or more physical comorbidities. There was a racial survival disparity from the time of MBC diagnosis, White women had an overall survival of 41.2 months (3.4 years), while Black women had an overall survival of 19 months (1.6 years). The most prevalent poor quality EOL care indicators were: 1) hospice enrollment three days or less prior to death, 2) admitted to the ICU in the last 30 days of life, and 3) death occurring in the acute care setting.

Of the demographic factors, increasing age at MBC diagnosis was correlated to a higher incidence of ICU admissions 30 days prior to death (p=0.03) and trended towards significance with more than one hospital stay 30 days prior to death (p=0.06). Black women were also more likely to experience each poor quality EOL care indicator as compared with White women. Endorsement of spiritual affiliation increased the likelihood of experiencing one or more ER visits (4.2 times), hospital admissions (1.9 times), and ICU admissions (3.9 times) in the last 30 days of life and was associated with death occurring in the acute care setting (3.1 times). Patients from neighborhoods of more deprivation were more likely to experience delayed hospice referrals (p=0.02). Married patients were 4.1 times more likely to receive any chemotherapy in the last 14 days of life. The presence of even a physical (p=0.001) or mental health (p=0.002) comorbidity were associated with delayed hospice referrals. For clinical factors, patients with negative ER status tended to receive both new chemotherapies in the last 30 days of life and any chemotherapy in the last 14 days of life.

Specific Aim 2 – For the QODD survey, a majority of the DPR participants were male (72%, n=18), the spouse of the deceased MBC patient (64%, n=16), White (98%, n=23), and had an average of 59.84 years of age. Total survey scores ranged from 13-216, having a total possible amount of 240. The average of scores was 137.28.

Specific Aim 3 – There were sixteen interviews conducted. Primary categories that emerged describing high quality care at the end-of-life were sources of resilience, communication experiences, supportive systems, and knowledge regarding both disease, treatment, and bereavement care. There was minimal frustration or regret verbalized around experiencing poor quality EOL care indicators (i.e., acute care utilization, aggressive chemotherapy, and minimal hospice care). However, there was a verbalized need for having

EOL care discussions, regardless of difficulty, as many acknowledged they would have felt more prepared.

Specific Aim 4 – In response to the question, "did your loved one discuss her wishes for EOL care with her doctor?," 75% (n=12) answered "yes," 18.8% (n=3) answered "no," and 6.2% (n=1) answered, "I don't know." While the majority of survey responses reported that "yes" (n=12; 75%), patients were able to discuss their EOL care wishes with their physician, and that this was an above average experience (n=8; 66.7%), the comments and perceptions surrounding such conversations were somewhat incongruent with the quantitative data. When asked to describe these conversations further, the DPR considered them unsatisfactory or extremely limited in content, focusing more on care decisions rather than prognosis. The omission of any prognostication on the part of the physician, ultimately left the patient and DPR without clear direction. Furthermore, upon reflection by the DPR, this lack of direction was more burdensome than anything else.

The stakeholder feedback group reported several barriers to achieving meaningful goals of care discussions during the trajectory of metastatic breast cancer care. These barriers included individual providers (i.e., communication difficulties, provider resistance, lack of training), system-wide issues (i.e., clinical time allotment, charting inconsistencies), and current widespread beliefs regarding the nature of metastatic disease.

Conclusion

The perception surrounding the quality of care received at the EOL can vary for each patient and DPR. It is vital to ensure that goal concordance is discussed long before EOL care is required with both the patient and the DPR. Consideration of the individual patient wishes and

how adherence to those wishes promote a high-quality EOL care experience will need to be further examined in future studies.

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LIST OF ABBREVIATIONS

Advance Practice Providers (APP)

Advance Care Planning (ACP)

American Society of Clinical Oncology (ASCO)

Completely at Random (MCAR)

Designated Personal Representative (DPR)

Electronic Health Record (EHR)

Emergency Room (ER)

End of Life (EOL)

Estrogen Receptor (ER+/-)

Events per Variable (EPV)

Goals of Care (GOC)

Healthcare Providers (HCP)

Human Epidermal Growth Factor Receptor 2 (HER2)

Intensive Care Unit (ICU)

Institutional Review Board (IRB)

Metastatic Breast Cancer (MBC)

Missing at Random (MAR)

National Cancer Institute (NCI)

National Comprehensive Cancer Network (NCCN)

National Institute of Nursing Research (NINR)

Neighborhood Deprivation Index (NDI)

Office of End-of-Life and Palliative Care Research (OEPCR)

Physician Order for Life-Sustaining Treatment (POLST)

Principal Investigator (PI)

Progesterone Receptor (PR)

Protected Health Information (PHI)

Quality of Death and Dying Questionnaire (QODD)

Registered Nurse (RN)

Support, Education, and Advocacy (SEA) Program of Care

Socioeconomic Status (SES)

Variance Inflation Factor (VIF)

PREFACE

I would like to thank each and every one of my committee members for their endless support, direction, and mentorship. Their assistance has made every part of this dissertation possible. First, thank you to my dissertation chair, Dr. Margaret Rosenzweig, whose mentorship, and expertise allowed me to dream, explore, and accomplish so much more than I could ever imagine. Thank you for believing in my work every step of the way. You are and will always be an example of what an excellent nurse scientist should be. Thank you to Dr. Jennifer Seaman, your tireless dedication towards my qualitative research was tremendous; Dr. Kathleen Lindell, for your thoughtful approach to my work and gracious encouragement; and to Dr. Susan Sereika, for your guidance in my analysis approach and persistent support. Thank you also to my consulting committee members, Dr. Annette Dabbs, for your expertise and wisdom with mixed methodologies and Dr. Adam Brufsky, for your expertise and dedication in improving the lives of those with metastatic breast cancer. Finally, to my fellow PhD cohort: thank you for your constant support, feedback, and brainstorming sessions.

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and sister, Reed, Anne, and Rebekah Heckmann, without you three, I would have never been able to accomplish this dissertation. Your encouragement, support, love, and kindness have carried me through each and every part of the journey.

1.0 INTRODUCTION

Death and dying have always been a part of the natural world and our human experience. Ultimately, it is one of the foundations of our civilization. However, the approach and beliefs surrounding such an event look vastly different nation to nation, culture to culture, and person to person (Howarth, 2007). This has, therefore, made the definition of quality care at the EOL incredibly difficult to universally capture. Understanding, too, that the differences and complexities of how societies have cared for their dying and its evolution throughout history, will often reflect the current culture in which the death is experienced (Copp, 1998). Particularly within large and complex Western societies, medical advancements and technologic improvements have led to the technologic imperative including the use of available therapeutics without full consideration of the illness context (Bryant, 2003; Lofland, 1978). The widespread utilization of aggressive care for life extension in metastatic cancer has redefined patient and family expectations. In previous years, metastatic cancer yielded a medical admonition to patients to "get your affairs in order." Therapy has now evolved to offering multiple, sequential therapies extending survival time. These therapies are offered in sequence with each progression diminishing the likelihood of success. Patients and family's expectations for metastatic cancer care have slowly evolved with these metastatic breast cancer treatment paradigms.

An appraisal of the current quality indicators for cancer treatment across the care continuum is necessary. This appraisal can look different for specific diagnoses and cancer

stages and will continue to be influenced by the current cultural, social, structural, and ethnic climates (Brown et al., 2018; Johnson, 2013; Krakauer et al., 2002; Wang et al., 2018). For instance, the present-day high quality indicators for early-stage cancer therapies include state of the art diagnostic tools, therapeutic interventions, and rehabilitation services, while poor quality indicators at the EOL for patients with advanced cancer include preventable acute care medical encounters in the last month of life (i.e., more than one ER admission, more than one hospital admission, an intensive care unit (ICU) admission, and death occurring in the acute care setting), delayed hospice referrals in those nearing the EOL, and/or aggressive chemotherapy utilization in the last month of life (i.e., a new chemotherapy in the last 30 days of life or any chemotherapy administered in the last 14 days of life) (Earle et al., 2005, 2008).

In the past, these two ends of the care spectrum were relatively well differentiated. However, with the advent of bone marrow transplantation, and aggressive chemotherapy requiring maximum support, adaptive t-cell therapies, which often results in intensive care admissions, and an array of targeted therapies with heavy symptom burdens often administered to patient with late-stage disease, these lines are no longer distinct (Rettig et al., 2007). Ultimately, the perception of quality care by providers, patients, and families may no longer be the absence of aggressive care, but the concept of "trying everything" which then encompasses necessary acute care and intensive care admissions, even if close to the end-of-life (Bergqvist & Strang, 2019; Ginter, 2020).

Specifically, within an MBC population, the quality of EOL indicators may have also shifted in recent years. Improved diagnostic processes, an explosion of treatment options for all disease subtypes, and more attention to the needs of population demographics all has lent itself to an increase in diagnosis and disease management complexities (Bredin et al., 2020; McAndrew

& Finn, 2020). Ultimately, MBC providers must adjust their care and healthcare practices to the unique and current circumstances surrounding women diagnosed with MBC. Moreover, quality indicators developed before the utilization of currently available MBC treatment options need to be reconsidered. The patient experience and the family voice are truly important for this modern adaptation.

1.1   SPECIFIC AIMS

Patients with metastatic cancer often receive aggressive, sequential life prolonging care, often until very near death (Huang et al., 2017; Nipp & Temel, 2017; C. E. P. Smith et al., 2019). This care is potentially costly, toxic, and may be inappropriate if not in congruence with the patient's GOC wishes. There are quality indicators for optimal EOL cancer care yet these indicators may not be appropriate with today's multiple treatment options for patients with cancer at the EOL (Earle et al., 2004; Ferrell et al., 2016). MBC, with a recent increased number of therapeutic options for all tumor subtypes, is an excellent prototype for this analysis.

Therefore, the first proposed study will utilize a retrospective analysis of recently deceased patients with MBC to ascertain if quality EOL indicators were included and adhered to during the MBC illness until death. The second study will provide data regarding the quality of EOL care and death experienced through the perspective of the DPR. The third study will utilize a mixed methods approach, utilizing the QODD survey responses and a qualitative inquiry regarding the EOL and death experience as perceived by the DPR. Lastly, these findings will be integrated into up-to-date recommendations for quality EOL care standards incorporating current treatment practices and challenges with the patient and family voices.

Specific Aims: The proposed study will examine EOL care through four specific aims:

1) Perform a retrospective chart review of demographic, social, patient health, and clinical factors of deceased MBC patients to assess for EOL quality indicators;

2) Determine the DPR's assessment of the quality of EOL care and death experience via the Quality of Death and Dying Questionnaire (QODD);

3) Explore the DPRs own, and their perception of the patient's view of EOL care and death quality through a qualitative semi-structured telephone interview;

4) Integrate the findings from Aims 1, 2, and 3 to achieve a comprehensive description and protocol for current EOL care for women with MBC and to have that protocol evaluated by key MBC stakeholders.

1.2   BACKGROUND, SIGNIFICANCE, INNOVATION

1.2.1   Quality in Health Care

While the definition of what constitutes healthcare quality can be stated broadly, the implementation of its definition is much harder to systematize uniquely amongst various population groups (Allen-Duck et al., 2017; Boulkedid et al., 2011). This has led to the development of specific quality indicators, which can vary depending on the population or region for which it is intended. These quality indicators are created through non-systemic (i.e. case studies and/or incidents) or systemic methods (i.e. current evidence available and/or expert

opinion) (Boulkedid et al., 2011). Consolidating these quality indicators together, thus allows for guidelines and protocols to be developed.

Creating these guidelines has allowed for standards of care and the direction of that care to be disseminated widely, establishing a treatment consensus among the experts in that particular field (Tobe et al., 2013; Vijayananthan & Nawawi, 2008). While it is important to establish guidelines to direct the current delivery of care, however, these guidelines and quality indicator components must also be adjusted to adapt with the evolving healthcare system and the population it serves.

1.2.2 Background Overview

Receiving an MBC diagnosis is a devastating moment that brings with it the tension of wanting to receive life extending therapy with minimal distress while maintaining hope. The exponentially growing options for MBC treatment, allows health care providers to continue to offer sequential treatments in attempts to prolong life (El Saghir et al., 2011; Otte et al., 2017; Santa-Maria & Gradishar, 2015). However, the long list of treatment options can delay the provider's discussion of prognosis, likely disease trajectory, and preparation for EOL care (van der Velden et al., 2020). Additionally, the patient themselves may wish for only positive news or at least want to be given a sense that something else is available for them to try (Collins et al., 2017). These wishes are dynamic for patient and families and can change throughout the disease course (Bergqvist & Strang, 2019; Schofield et al., 2006). Therefore, the challenge for healthcare providers is balancing the provision of care and maintenance of hope with the need to honestly communicate severity of the disease and prognosis (Ginter, 2020; Ray et al., 2006).

MBC is a progressive, non-curative disease, with multiple treatment options. Treatment for MBC has evolved from broad patterns of chemotherapy and palliative radiation, to precision targeted and hormonal therapies in efforts to continually increase the length of survival (Caswell-Jin et al., 2018; Chen et al., 2017). Prognosis predication is further compounded with regard to MBC subtypes (Alečković et al., 2019; El Saghir et al., 2011; Miller et al., 2016). Subtypes in breast cancer represent the categorization of estrogen and HER2 protein markers into four categories representing different epidemiological risk factors, natural histories for disease progression, and ultimately, varying responses to systemic and local therapies (Dent et al., 2009; Lobbezoo et al., 2013; Plevritis et al., 2018; Sotiriou et al., 2003). Gene expression profiles, associated organ-specific relapses, and even type of metastatic spread are influenced by these various subtypes (Alečković et al., 2019; Laohavinij et al., 2017; Partridge et al., 2016; Santa-Maria & Gradishar, 2015; Smid et al., 2008). Therefore, treatment algorithms, such as those from the National Comprehensive Cancer Network (NCCN), are derived based on tumor subtype and can include hormonal therapy, chemotherapy, targeted therapy, immunotherapy, and radiation therapy (Etan et al., 2020; Gradishar et al., 2015).

The toxicities and side effects from these therapies, as well as the signs and symptoms of advancing cancer, can cause patient related distress (El-Jawahri et al., 2020; Haque et al., 2020; Torre et al., 2017). The treatment and disease related side effects are therapy, cancer site, and comorbidity dependent (Sarfati et al., 2016). It is important that the toxicity profile be assessed frequently to assure that the patient experienced toxicities are acceptable to the patient and families' goals of care. It is imperative, therefore, with the treatment opportunities, toxicities, side effects, and subsequent patient expectations, that the quality of MBC current treatment standards, particularly at the EOL, be evaluated over the course of illness to maintain patient-

centered goal concordance (Borreani et al., 2012; Clayton, Butow, Arnold, et al., 2005; El-Jawahri et al., 2017; Steinhauser et al., 2000).

Along with multiple tumor and disease factors, demographic, social, patient health, and clinical factors can impact the quality of EOL care. These factors include age, (Dialla et al., 2015; Falchook et al., 2017; Miesfeldt et al., 2012), race, (Abdollah et al., 2015; Miesfeldt et al., 2012), neighborhood deprivation, (Dialla et al., 2015; Zhang et al., 2018), marital status, (Dinh et al., 2018; Li et al., 2015; Qiu et al., 2016), spiritual affiliation, (Hong & Cagle, 2019; LeBaron et al., 2015; Rohani et al., 2015), and the presence or absence of comorbidities (Fu et al., 2015; Sarfati et al., 2016; Wachterman et al., 2016). As the disease progresses and EOL care is required, these factors will have an increasingly important influence on the preference and consistency of goal concordant care, method of treatment delivery, and death context (Khandelwal et al., 2017; Parr et al., 2010a). Competing personal needs, prioritizing of resources (e.g. time, money, transportation, distance from care), and geographically associated barriers can also affect access to care and availability of providers, thereby diminishing the quality of MBC care (Brown et al., 2018; Chang et al., 2014; Lin et al., 2015). To better understand how to adapt quality standards to meet today's care expectations and improve communication pathways between the healthcare providers and individuals, it is vital that each of these areas are considered.

To begin addressing these EOL care needs, standards of care were established and recommendations provided. One such organization, the National Institute of Nursing Research (NINR) and its Office of End-of-Life and Palliative Care Research (OEPCR), championed the priority of integrating palliative care within chronic care treatment plans, assisting in decision-making, and relieving burdensome symptoms and suffering for those diagnosed with a life-

limiting illness (Bakitas et al., 2009). The current quality indicators and concepts established for EOL care and a good death have also come from the American Society of Clinical Oncology (ASCO) and Earle's research on the three themes of a poor quality advanced cancer death (Earle et al., 2003; Ferrell et al., 2016). In 2003, now 18 years ago, Earle's metrics were established to measure the quality of EOL care objectively and through available administrative data. Earle's three themes of poor-quality advanced cancer care were measured into seven quantifiable indicators. These indicators include: new chemotherapy received in the last 30 days of life, any chemotherapy received in the last 14 days of life, more than one emergency room visit in the last 30 days of life, more than one hospital stay during the last 30 days of life, admission to the intensive care unit in the last 30 days of life, hospice enrollment only three days or less prior to death, and death occurring in the acute care setting (Earle et al., 2003).

In order to meet these quality indicators during MBC care, the care delivery team is vitally important. The treatment team serves as the means to deliver EOL care and may be diverse in specialties and expertise, including but not limited to the oncologist, radiation oncologist, consulting physicians, physician assistants, nurse practitioners, registered nurses, and social workers. Collaboratively, the team is essential for providing knowledge around 1) diagnosis; 2) anticipatory guidance for disease management; 3) assistance in navigating insurance and financial needs; 4) any competing social and personal needs; and 5) EOL care planning and implementation (Funk-Lawler & Mundey, 2020; Krigel et al., 2014; Reiser et al., 2019a). The team needs to consider all of these factors when incorporating EOL care into MBC disease treatment and EOL care.

Ultimately, regardless of the oncology staff and interdisciplinary team, the timing of the integration of meaningful EOL care standards for women diagnosed with MBC can still remain

challenging. In MBC, there is a wide variability in tumor subtype, (El Saghir et al., 2011; Kennecke et al., 2010; Laohavinij et al., 2017), disease prognosis, (Johansson et al., 2019; Lobbezoo et al., 2013; Nahid Nafissi, 2016), treatment options, (El Saghir et al., 2011; Peppercorn et al., 2008), and patient and family characteristics and expectations (Bernacki & Block, 2014; Chung & Carlson, 2003; Hancock et al., 2007). Moreover, the current standards against which EOL care quality is being measured may not accurately reflect 1) the current MBC treatment possibilities, 2) the healthcare system and providers, or 3) give adequate enough voice to the patient and DPR's expectations.

1.2.3 Significance

1.2.3.1 Accuracy of Current EOL Quality Care Indicators for the MBC Population

While Earle's seven poor quality EOL care indicators are used to define EOL care quality in multiple populations, it is not clear if these indicators are accurate in describing current MBC populations and their experiences at the EOL (Earle et al., 2004). Therefore, it is vital to evaluate the care received by women deceased from MBC using the defined poor quality EOL care indicators while simultaneously examining the quality of EOL care and the death experience as perceived by those closest to the deceased, that is, the DPR. By comparing these complimentary and distinct data sets, the accuracy and innovation of the poor quality EOL indicators may be established. Moreover, additional information may be gathered from the DPR that could provide supplementary metrics and suggestions for improvement in measuring EOL care quality for the MBC population in a novel approach.

1.2.3.2 Lack of Consensus Regarding Integration of EOL Care

The integration of palliative care into advanced cancer care is considered to be quality care (M. H. Levy et al., 2012). Moreover, providing early palliative care can lead to meaningful changes to the patient's quality of life and EOL care (Emiloju et al., 2020; Sullivan et al., 2019; Temel et al., 2010). Meaningful palliative care should include not only disease and symptom management but also a thorough examination of "psychological, existential, and social aspects" (Pask et al., 2018). The treating oncology team may have definite ideas of how they want their patient's treatment and care management to proceed and limit the input from the palliative care team for discussion of prognosis or the plan of care (Bruera & Hui, 2012; Muir et al., 2010).

1.2.3.3 Timing of integration of EOL care

This study is significant and will be an important contribution because the EOL care timing will be assessed in the retrospective study. Optimal timing for and components of EOL care discussions will be interrogated in the discussions with the DPR.

1.2.3.4 Influence of the Designated Personal Representative

In addition to the individual patient experience, the patient's DPR possesses insight into the patient's perceptions regarding disease progression, treatment decisions, and deciding the components of quality EOL care and the death experience (Bernacki & Block, 2014; Dionne-Odom et al., 2019; Van Eechoud et al., 2014). In this instance, the DPR could be anyone who is the patient's closest support and can include, a spouse, partner, parent, child, sibling, extended family member, or friend. These perceptions may be unlike what is currently defined by caregiver models and conceptual frameworks and may be especially dependent on the patient's as well as DPR's demographic, social, patient health, and clinical factors. Ultimately, this

unique, significant perspective can be lost once the patient is deceased and there is no further contact with the decedent's family or support system.

1.2.4   Innovation

This innovative project was designed to assess the quality of advanced cancer and EOL care. This project was created for the purpose of shaping MBC advanced cancer and EOL care standards to reflect current treatment options and to improve the quality of EOL care and the death experience. In today's medical oncology clinics, palliative care is now offered as an integrated or referral service, but the visits are often centered on opiate use or symptom management, and for a variety of reasons, comprehensive discussions of goals of care are not completed (Brazee, Rachel L., Sereika, Dr. Susan M., & Rosenzweig, 2021; Shah, 2018). The barriers that inhibit the use of meaningful palliative care, which includes an EOL goals discussion, are not well defined and therefore, difficult to mitigate (Cleeland et al., 2014; Haun et al., 2017; Mosher et al., 2013; Park et al., 2018; Reed et al., 2012; Sorensen et al., 2012; Thoonsen et al., 2015). This innovative study will analyze EOL care and death experiences by:

- Examining the unique disease and treatment associated burdens found in the MBC population.
- Include the DPR's perspective and narrative around their loved one's diagnosis, treatment, and ultimately, death.
- Establish tangible variables predictive of poor EOL care and death experiences.
- Lay the foundation for informing the development of future interventions and decision-making tools for healthcare professionals to optimally integrate a goals of care discussion in the patient's treatment trajectory.

Integrating these data points and perspectives will allow for the construction of EOL care quality

standards for women diagnosed with MBC. This is turn can help healthcare systems and MBC

providers integrate patient derived quality standards to reflect current MBC advanced cancer

care.

1.3   CONCEPTUAL FRAMEWORK

To understand the dynamic and complex concepts surrounding the quality of EOL care

and the death experience, three conceptual frameworks or models were chosen to give an

underlying structure to the proposed study. These frameworks include Emanuel & Emanuel's

Framework for a Good Death, the Quality of Dying and Death conceptual framework, and the

Cancer Family Caregiving Experience Conceptual Model (Emanuel & Emanuel, 1998; Patrick et

al., 2001).

Emanuel & Emanuel's Framework for a Good Death will serve as the theoretical model

for the first arm of the proposed study (Emanuel & Emanuel, 1998). The Framework for a Good

Death was created in 1998 to better conceptualize the three factors influencing the death

experience: 1) fixed characteristics of the patient (e.g., demographic, social, patient health, and

clinical factors), 2) modifiable dimensions of the patient's experience (e.g., physical symptoms,

hopes and expectations, etc.), and 3) care-system interventions (e.g., family and friend

interventions, social interventions, etc.). The outcome of the framework, the overall death

experience, is multifaceted. The specific indicators of poor quality EOL care in patients with

cancer were derived from a literature review, focus groups with cancer patients and family

members, as well as with an expert panel and include: 1) potentially preventable medical

encounters in the last month of life, 2) delayed hospice referrals in those nearing the EOL, and 3) aggressive chemotherapy utilization in the last month of life (Earle et al., 2003). These were further dissected into seven measurable EOL care indicators: new chemotherapy received in the last 30 days of life, any chemotherapy received in the last 14 days of life, more than one ER visit in the last 30 days of life, more than one hospital stay during the last 30 days of life, admitted to the ICU in the last 30 days of life, hospice enrollment only three days of less prior to death, and death occurring in the acute care setting. For this study, these two aspects were then merged to form an adapted framework for a Good Death using Earle's poor quality EOL care indicators to assess the MBC population.

Fixed characteristics of the MBC patient:

Clinical factors
Tumor subtype (ER and HER2 status)

Demographic, Social, and Patient Health factors
Age at metastatic diagnosis
Race
Spiritual Affiliation
Neighborhood Deprivation Index (NDI)
Marital Status
Employment Status
Insurance status
Comorbidities

Poor quality of end of life care indicators (Earle, 2008):

Potentially preventable medical encounters
1. Death in an acute care setting
2. More than one ED visit 30 days before death
3. More than one hospital admission 30 days before death
4. At least one ICU admission in the last 30 days of life

Aggressive chemotherapy utilization
5. New chemo 30 days before death
6. Any chemo 14 days before death

Delayed hospice referrals
7. Hospice care less than 3 days before death

Adapted from Framework for a Good Death (Emanuel and Emanuel, 1998)

Figure 1: Good Death Model Adapted Theoretical Framework

For aim 2 and 3, the quality of EOL care and the death experience will be examined through the perspective of the DPR. Because of this approach and perspective, the Quality of Dying and Death conceptual framework and the Cancer Family Caregiving Experience conceptual model were chosen (Fletcher et al., 2012; Patrick et al., 2001). The main tenants of the Quality of Dying and Death framework consist of six domains: 1) symptoms and personal care; 2) preparation for death; 3) moment of death; 4) family (i.e., spending time with family

members, pets, or being alone, familial structure, etc.); 5) treatment preferences; and 6) whole person concerns (Patrick et al., 2001). These domains can be applied to both the preferences prior to death and the perspective of the quality of dying and death after the death has occurred. The QODD survey instrument was created from these domains.
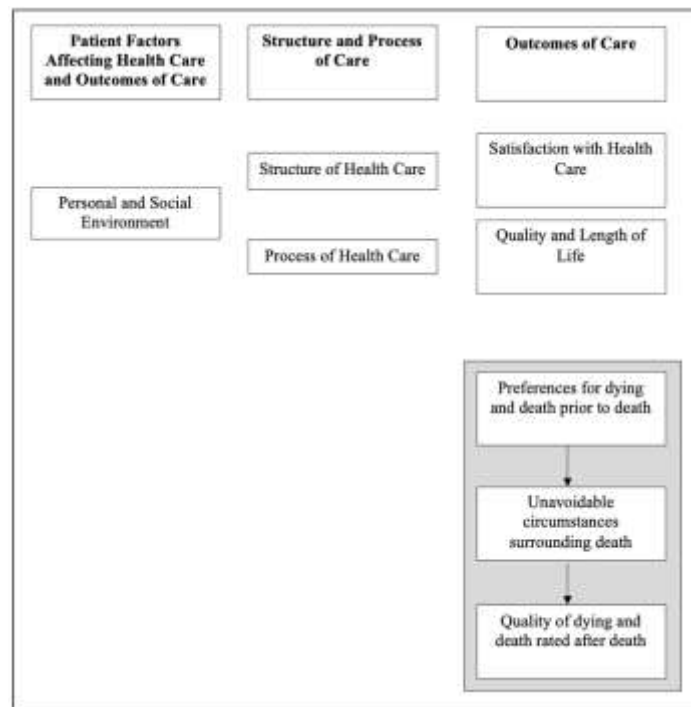
Figure 2: Quality of Death and Dying (QODD) Survey Instrument Domains

In 2000, Weitzner, Haley, and Chen published the original model of the Cancer Family Caregiver, based on the ever-expanding research regarding the role of caregivers throughout the 1990s (Weitzner et al., 2000). This conceptual model focused on the family caregivers of older adults and their cancer-specific stressors. These researchers proposed that the diagnosis of cancer can affect any dynamic within the family, such as identity, roles, and daily functioning. In response to the fluctuating dynamics throughout their loved one's treatment, careful attention to primary or secondary stressors of the caregiver can help to reduce overall caregiver burdens. These burdens can include financial needs, lack of coping strategies and self-care behaviors, and

minimal support directed toward caregiver health and wellbeing. Ultimately, the authors found that due to family caregivers being essential for successful, comprehensive care of geriatric oncology patients, it is vital to be aware of these caregiver-related stressors.
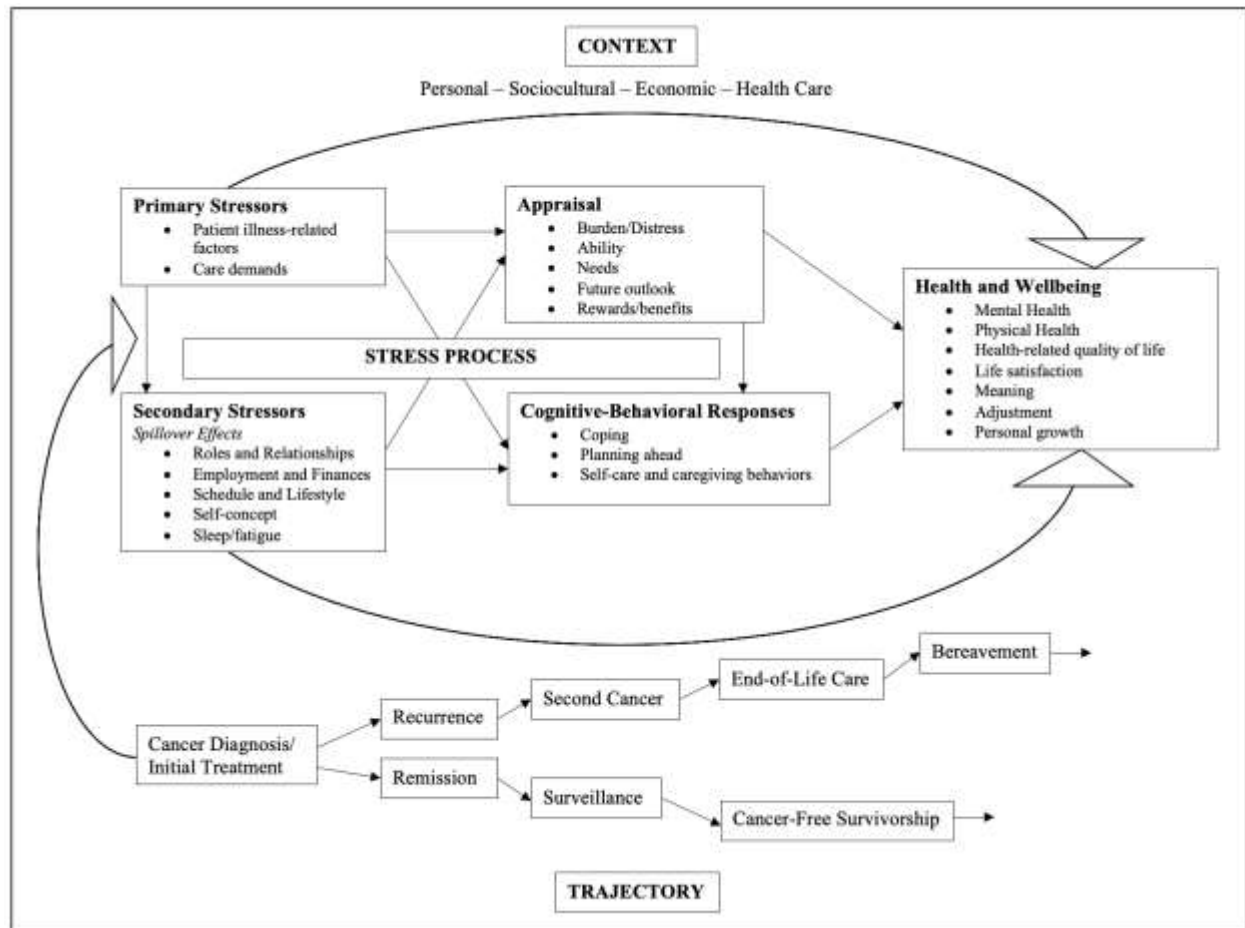
Figure 3: Expanded Cancer Family Caregiver Model

In 2010, the conceptual model was expanded according to the caregiver-specific research developed between 2000-2010 (Fletcher et al., 2012). The enhanced conceptual model found additional influences that affected the caregiver dynamic including, 1) the stress process; 2) contextual factors; and 3) the unique cancer trajectory as it relates to the caregiver. The term "caregiver" can encompass a close family member to a paid assistant. To avoid confusion in this study, we are suggesting that instead of the term "caregiver," the term designated personal

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representative (DPR) will be used. The DPR serves as the patient's chosen individual who can make healthcare related decisions on the patient's behalf as well as determine the uses and disclosures of the patient's protected health information. The DPR may also be the same as the "next of kin," however, this may not be true in all instances. Ultimately, it is through the careful examination of the DPR's motivations, contexts, and stress processes that this study captures the DPR's perspective on the patient's quality of EOL care and the death experience.

1.4   PRELIMINARY STUDIES

1.4.1   The Support, Education, and Advocacy (SEA) Program of Care for Women with Metastatic Breast Cancer: A Nurse-Led Palliative Care Demonstration Program (Reiser et al., 2019a).

Background: MBC is a heterogenic disease with multiple treatment algorithms and wide prognostic range due to tumor subtype, influencing both the initiation and continuation of supportive care services. However, due to patient and disease-related complexities, initiating and maintaining symptom management and psychosocial care throughout the treatment timeline can be challenging.

Objective: In an effort to identify needs and coordinate supportive care referrals and services for MBC patients, a one-hour weekly patient review meeting was initiated. These meetings were then used to assess potential patient care needs, including but not limited to, social services, psychological counseling, and palliative care.

Methods: This study was a pre- and post-program implementation assessment conducted at a southwestern Pennsylvania Designated Cancer Center outpatient breast cancer clinic. The MBC Program included a review of the symptoms, care needs, and potential needed referrals for social work, palliative care, and clinical trials of patients diagnosed with MBC who were outpatients scheduled for clinic in the following week. The assessments analyzed were routine care to capture patient reported outcomes, symptom distress, generalized anxiety, and overall well-being. The surveys were administered to patients at the beginning of their appointment (via iPad technology and deposited into the patient electronic records). Cumulative symptoms, care needs, referrals to social work, palliative care, enrollment into clinical trials, emergency department visits, and calls to clinics were assessed pre- and post- program implementation.

Results: The MBC Program of Care was instituted in October 2016. A preprogram implementation assessment of symptoms, anxiety, overall well-being, and referrals to palliative care, social work, and clinical trial recruitment was conducted between August 2016 to October 2016. After a 3-month implementation, the post assessment was February 2017 to April 2017. The total cohort of the study was 118 women. Following the implementation of the nurse-led weekly review meetings, there was a significant increase for referrals to palliative care (p=0.002) and social work (p<0.005) supportive services. Additionally, there was improvement to patient-reported symptom burden (p=0.004), overall well-being (p=0.033), reduction in Generalized Anxiety Disorder Scale (p=0.003), fewer emergency department visits, and fewer calls to the clinic. Admissions to the acute care setting and clinical trial recruitment did not change.

Conclusion: Individualized and intentional care for the MBC population has allowed for utilization of existing programs to meet social and palliative care needs. These referrals were associated with improved patient-reported outcomes.

1.4.1.1 Implications to the Proposed Dissertation Study

The preliminary study results are important because they indicate 1) current levels of distress and symptoms, 2) the poor pattern of referrals to needed supportive services and 3) the potential for improvement with focused attention to care needs. It is through the examination of 1) current trends of EOL care utilization and 2) a perspective from the patient's loved ones regarding the EOL care quality and death experience that will allow for treatment care gaps to be holistically addressed, interventions carefully individualized, and an EOL care MBC protocol to be established.

1.4.2 Summary

1.4.2.1 Shortfalls of the Current Oncology End-of-Life Care System

The current methods to measure the quality of EOL care does not fully capture the modern needs and experience of women diagnosed with MBC as they progress through illness and approach death. Moreover, current clinical care, documentation and data capture allows little opportunity to optimize and individualize treatment according to each patient and their preferences. It appears that patients are offered treatments in a sequential fashion but without meaningful assessments regarding their individualized EOL needs. Based on this need, additional work is required to understand 1) the current MBC care patterns at the EOL, and 2) the unique barriers, burdens, and care goals for women diagnosed with MBC from the perspective of their DPR. We will then bring together these data and voices to create the foundation for establishing a protocol for current EOL care for women with MBC.

1.5   RESEARCH DESIGN AND METHODS

1.5.1   Study 1: Retrospective Chart Review Study Design

1.5.1.1 Study Design

The study design is a retrospective chart review of data retrieved from the EHR of patients deceased from MBC between November 1, 2016, through November 30, 2019. The chart review dates selected were concurrent with the start of an interdisciplinary *Metastatic Breast Cancer Program of Care,* a weekly patient review meeting that began in October 2016 (Reiser et al., 2019b). These review meetings identify and link patients to the necessary supportive care services (e.g., palliative care, financial care, or social work). Following the Good Death Model, the aims of this study are to assess *demographic factors* (age at MBC diagnosis, age at death, race, sex), *social factors* (spiritual affiliation, neighborhood deprivation score derived from zip code, and marital, employment, and insurance status), *patient health factors* (mental health comorbidities, physical comorbidities), *clinical factors* (tumor type: ER and/or HER2 status, length of survival), *supportive care factors* (palliative care [presence], social work [presence], advance directives [presence], and goals of care discussions [if occurred, length of time prior to death, times occurred], and quality *EOL care indicators* (hospice care [presence, length of time], place of death, Intensive Care Unit (ICU) admission 30 days or less prior to death, new chemotherapy in the last 30 days of life, any chemotherapy in the last 14 days of life, more than one ER visit in the last 30 days of life, and more than one hospital admission in the last 30 days of life) of MBC patients.

1.5.1.2 Study Setting

The study will be conducted at a southwest Pennsylvania cancer clinic of a National Cancer Institute designated cancer center. Participants will include women deceased from MBC between November 1, 2016, through November 30, 2019, who were treated at the cancer clinic.

1.5.1.3 Study Sample

1.5.1.3.1 Subject Inclusion, Exclusion, and Data Collection Protocol

Inclusion criteria were women: 1) 18 years of age or older; 2) diagnosed with MBC, including de novo diagnosis (metastatic at diagnosis) or diagnosis of MBC after a previous diagnosis of stage I-III breast cancer; 3) received oncology treatment at a southwest Pennsylvania academic clinic; and 4) death occurring November 1, 2016, through November 30, 2019.

Exclusion criteria will include patients who were: 1) male and 2) whose treatment course was not directed at the cancer clinic. Male MBC patients were not included as this study sought to specifically capture the quality of EOL care for female patients. Patients who came for a consult or second opinion only will be excluded due to limited availability of MBC treatment information.

All data collection will be performed by the principal investigator (PI). Any data from the medical record requiring clarifications will be discussed with a senior member of the research team, who is also a clinician in the cancer center. To verify and assess accuracy of the data, 10% of the sample will be randomly selected and reviewed by another registered nurse (Vassar & Matthew, 2013). Any identified discrepancies or uncertainties will be discussed and consensus reached. Data screening procedures will be conducted to initially analyze the data for any

missing components or conflicts. To complete any missing data, the research team will return to the original EHR source.

1.5.1.3.2 Sample Size Justification

The purpose of this research study is to describe quality of EOL care and the death experience. Each one of the categories of interest (i.e., the patient's demographic, social, patient health, clinical, and EOL care indicators) must be considered.

With relation to Aim 1, the assumption of the sample proportion cut will be 0.500 and the confidence interval will be set at 0.95. Additionally, the actual width will be conducted at 0.165, which is equal to the total margin of error. For the sample size estimation, the 10:1 rule and the g*power for sensitivity analysis will be used. Adjusting for covariates, each predictor should have a minimum of ten cases. For example, if fifteen predictors are to be considered, a sample of one hundred fifty cases should be collected. For g*power, the analysis would use a two-tailed test, with a R^2 of 0.001, an alpha = 0.05, a 0.80 power, and an odds ratio (effect size) of 0.464. To achieve adequate power according to a g*power analysis, a total sample of 55 participants would be required.

1.5.1.4 Variables

1.5.1.4.1 Defining the Independent Variables

The independent variables will be examined to assess their impact or relationship to the dependent variables, EOL care, and death quality. For the retrospective chart review component of the study, the independent variables will include the deceased MBC patient's: 1) *demographic factors* (age at MBC diagnosis, age at death, race, sex), 2) *social factors* (spiritual affiliation, neighborhood deprivation score derived from zip code, and marital, employment, and insurance

status), 3) *patient health factors* (mental health comorbidities, physical comorbidities), 4) *clinical factors* (tumor type: ER and/or HER2 status, length of survival), 5) *supportive care factors* (palliative care [presence], social work [presence], 6) *advance directives* [presence], and 7) *goals of care discussions* [if occurred, length of time prior to death, times occurred]).

1.5.1.4.2 Defining the Dependent Variables

The dependent variable is the quality of EOL care and the death experience as determined by the quality EOL care indicators of Earle's work (i.e., death in the acute care setting, Intensive Care Unit (ICU) admission 30 days or less prior to death, hospice care 3 days or less before death, new chemotherapy in the last 30 days of life, any chemotherapy in the last 14 days of life, more than one ER visit in the last 30 days of life, and more than one hospital admission in the last 30 days of life). Outcomes of these indicators will be measured through a protocolized review of both EHR and meeting notes from the *Metastatic Breast Cancer Program of Care,* a weekly patient review meeting.

1.5.1.5 Methods

The PI will extract EHR data from a southwestern Pennsylvania designated cancer center outpatient clinic to quantify *demographic factors* (age at MBC diagnosis, age at death, race, sex), *social factors* (spiritual affiliation, neighborhood deprivation score derived from zip code, and marital, employment, and insurance status), *patient health factors* (mental health comorbidities, physical comorbidities), *clinical factors* (tumor type: ER and/or HER2 status, length of survival), and *EOL care indicators* (palliative care [presence, length of time], hospice care [presence, length of time], social work [presence, length of time], place of death, ICU admission 30 days or less prior to death, new chemotherapy in the last 30 days of life, any chemotherapy in the last 14

days of life, more than one ER visit in the last 30 days of life, and GOC discussion before death [if occurred, length of time prior to death, times occurred]) of MBC patients deceased between November 1, 2016 and November 30, 2019. The EHR will be accessed manually by the PI and verified by a second researcher.

1.5.1.6 Measures

For each variable, the measure, type, and descriptive statistics used are detailed below in Table 1.

Table 1: Deceased Metastatic Breast Cancer Patient Demographic, Social, Patient Health, Clinical, and EOL Care Indicators

Deceased Metastatic Breast Cancer Patient Demographic, Social, Patient Health, Clinical, and EOL Care Indicators			
Variable	**Measure**	**Type**	**Descriptive Statistics**
Age at MBC diagnosis (years)	Date of Birth	Ratio	Mean, SD Median, IQR (if non-normal)
Age at death (years)	Date of Death	Ratio	Mean, SD Median, IQR (if non-normal)
Race	Self-reported	Nominal	Frequency counts, percentages, mode, range
Sex	Self-reported	Dichotomous	Frequency counts, percentages
Spiritual affiliation	Self-reported	Nominal	Frequency counts, percentages, mode, range
Neighborhood Deprivation Score	Zip Code	Continuous	Mean, SD Median, IQR
		Dichotomous (Median)	Frequency counts, percentages
Marital Status	Self-reported	Nominal	Frequency counts, percentages, mode, range
Employment status	Self-reported	Dichotomous	Frequency counts, percentages
Insurance status	Self-reported	Dichotomous	Frequency counts, percentages
Mental Health Comorbidities	EHR Diagnosis List	Dichotomous	Frequency counts, percentages
Physical Comorbidities	EHR Diagnosis List	Dichotomous	Frequency counts, percentages
One or more ER visit in the last 30 days of life	Yes/No	Dichotomous	Frequency counts, percentages
One or more hospital admission in the last 30 days of life	Yes/No	Dichotomous	Frequency counts, percentages
ICU admission	Yes/No	Dichotomous	Frequency counts,

			percentages
Hospice care 3 days or less before death	Yes/No	Dichotomous	Frequency counts, percentages
New chemotherapy in the last 30 days of life	Yes/No	Dichotomous	Frequency counts, percentages
Any chemotherapy in the last 14 days of life	Yes/No	Dichotomous	Frequency counts, percentages
Death occurring in the acute care setting	Yes/No	Dichotomous	Frequency counts, percentages

1.5.1.7 Data Analysis Plan

1.5.1.7.1 Descriptive Statistics

Descriptive statistics, such as mean, standard deviation, and range, will be used to summarize the MBC cohort sociodemographic characteristics, clinical factors, and EOL care indicators.

1.5.1.7.2 Data Screening Procedures

The data will be initially analyzed for accuracy through four separate stages: proofreading, computation of descriptive statistics, range checking, and contingency checking. These processes will clarify understanding of the distribution and if the sample itself, makes "sense." Additionally, the data source will be interrogated for double coding/entry if inconsistencies are found.

1.5.1.7.3 Screening for Outliers

The data will then be examined for any outliers, as this can distort or inappropriately influence the summary and test statistics, cause type I and type II errors, and ultimately lead to results that may not be generalized after the findings are communicated. The detection of outliers will be done based on the type of measurement and dimensionality. In the case of univariate outliers, an observation which is extreme on only one variable, it can be further subdivided into

categorical and continuous variables. For categorical variables, frequency tables in SPSS will be conducted. For continuous variables, histograms, box plots, normality probability plots, and detrended normal probability plots will be conducted. In the case of multivariable outliers, a situation where there is an unusual combination of values on two or more variables, bivariate plots between pairs of variables will be conducted. If any outliers in the data are found, the PI will decide whether to continue utilizing the observation in the sample, whether the scores should be modified, or whether the entire observation will be deleted.

1.5.1.7.4 Missing Data

The next component of the data screening procedures will be to analyze the data for any missing components. To fill-in any missing data, the research team will return to the original electronic medical record source. After attempting to fill all possible missing information gaps, if data are still not found, the research team will discuss whether the missing information is vital to the analysis, whether inference is possible, and the amount, as well as distribution, of the missing data. The research team will then describe the pattern of missing data, as to whether it is related to single observation variables or longitudinal variables and whether it is missing at random (MAR) or completely at random (MCAR). Additionally, for longitudinal variables, it will also be analyzed if the data has bounded missing, multivariate missing, or univariate missing. Based on the pattern of missing data, determination of the most appropriate strategy for imputation would then be decided.

1.5.1.7.5 Checking for Underlying Assumptions

The underlying assumptions of binomial logistic regression will also be tested include the independence of observations, sufficient sample size in each category, linearity of any continuous independent variables with the log odds of having a poor quality of death, and multicollinearity. Normality can be assessed using measures of skewness, kurtosis, the Shapiro-Wilks test, Q-Q plots, and histograms. Independence will be assessed by using scatterplots. However, it should be noted that if the data are collected from randomly sampled individuals, it is generally assumed that the data are independent. To assess for linearity, nonlinearity can be discovered through residual plots such as studentized or standardized residuals. Finally, to assess for multicollinearity, we will examine the variance inflation factor (VIF). If the estimated regression coefficient value increases, the predictors are correlated. If the predictors are not correlated, then the VIF value will all be one. As a rule of thumb, VIF values that are greater than ten indicate multicollinearity, however, models that contain a value of 2.5 or above may also be reason to question the model.

1.5.1.7.6 Transformation of Data

Finally, data transformation can be utilized when the sample distribution is skewed or deviates from the normal distribution. The choice of data transformation (i.e., log, inverse, square-root) is dependent on the degree and direction of deviation. After any transformation is conducted, assumptions must be rechecked, category collapsing may be necessary, and the interpretation of results may have to be rescaled.

1.5.1.7.7 Data Analytics Procedures

To appropriately explore the relationship between variables, we have to consider the objective of the study. Using descriptive statistics, a cohort of women recently deceased from MBC will be described according to their demographic, social, patient health, clinical, and EOL care factors. Using binomial logistic regression, the association of poor quality EOL care indicators according to key demographic, social, patient health, and clinical factors among women recently deceased from MBC will be explored.

1.5.1.8 Preliminary Results

Preliminary study characteristics: Quality of Care for Patients Deceased from Metastatic Breast Cancer (MBC) (accepted abstract). Patient demographics, tumor, treatment, and supportive care referral utilization were extracted from the electronic medical record (EHR). These data were reviewed to determine the extent of treatment and resource utilization among all deceased MBC patients between November 2016 and May 2019. Unstructured progress notes were additionally extracted from the EHR and reviewed manually as needed to clarify indeterminate results. Preliminary data found 133 deceased patients with MBC in this time period. Due to pertinent missing data, six individuals were excluded from the final preliminary analysis.

In this cohort, age at diagnosis ranged from 29.6 years to 89.6 years of age, mean of 55.3 (*SD* 11.73). The majority of the sample, (n=86, 66.2%), were under the age of 65 years at the time of death. The cohort was 13% (n=17) Black and 87% (n=114) White. A majority of the sample reported a spiritual affiliation and were either married or partnered. All were insured. Within the sample, 23.1% (n=30) of the MBC cohort that had one or more mental health

comorbidity and over 63.8% (n=83) of the MBC cohort that had one or more physical comorbidities.

Quality care at the EOL: Among this population, 81.6% (n=107) had some palliative care service, 49.6% (n=65) had no advance directives, 39.6% (n=52) died without any hospice service, and 11.4% (n =15) died in the ICU. Of those in the ICU, 60% (n=9) did not have an advance directive, and 40% (n=6) had an initial goals of care meeting 2 months or less prior to their time of death.

1.5.1.9 Discussion

This rigorous and reproducible review process established outcome cases and quantified the characteristics of an MBC cohort, supportive care utilization (i.e., palliative care, social work, and advance directives), and quality of EOL care according to national standards. The proposed study will further analyze the relationship between patient characteristics and quality of EOL care.

1.5.2   Study 2: Quantitative QODD Survey

1.5.2.1 Study Design

The first component of the sequential quantitative-qualitative mixed methods study will be the QODD survey. This survey will be offered to a DPR cohort for women diagnosed and deceased from MBC.

1.5.2.2 Study Setting

Participants will be recruited from four groups: 1) a southwestern Pennsylvania designated cancer center outpatient clinic including the DPR of MBC patients deceased from November 2016 to October 2020, 2) a local Pittsburgh cancer support group for DPRs, and 3) two social media group platforms who focus specifically within the MBC population. Convenience sampling will be conducted at the southwestern Pennsylvania designated cancer center outpatient clinic which had approximately 177 patients who died between the selected time period. The DPR will be found from each of these MBC patients in their EHR. For the local Pittsburgh cancer support group and social medial group platforms, the snowball sampling method will be conducted. Ultimately, an unknown number of participants were contacted through these methodologies. However, the cancer support group, Young Survivor Coalition, has the potential to reach more than 170 networking groups and an online community. The Metavivor group has the ability to reach both online communities and during education and fundraising events. The Cancer Caring Center support group is able to operate multiple caregiver and grief workshops throughout the year.

1.5.2.3 Study Sample

1.5.2.3.1 Subject Inclusion and Exclusion

Inclusion criteria into the study sample will include 1) "next of kin" or "designated personal representative" as specified from the EHR for the Pennsylvania designated cancer center outpatient clinic for women deceased from MBC between November 1, 2016, and October 31, 2020, 2) age>18 years; and 3) for the cancer support groups and social media platforms, a self-reported DPR (whether a partner, spouse, family, or support person) for a

woman diagnosed with and deceased from MBC. There will be no restrictions based on race. The exclusion criteria are 1) any DPRs age<18 years of age, and 2) any DPRs for male MBC patients as this study is focusing on the female patient experience.

1.5.2.3.2 Sample Size Justification

To calculate sample size for this research study, it is important to consider several different areas: time, cost, feasibility, and objectives of the research study (estimation, hypothesis testing, or both). Additionally, we must also assess whether to conduct estimation-orientation sample size estimations or hypothesis testing-orientated estimations. Because the purpose of this research study is to describe quality of EOL care and the death experience, each one of the categories of interest (i.e., the patient's demographic, social, patient health, clinical, and EOL care indicators; and the DPR's demographic and survey responses) must be considered.

1.5.2.4 Methods

Recruitment – there will be multiple sites of recruitment.

1) Southwest Pennsylvania designated cancer center outpatient clinic - The deceased patient's name, birthdate, and date of death will be received from the clinic. Using those data, the contact information (i.e., name, address, and email) of the DPR will be retrieved from the EHR. For those DPRs that are found via the cancer clinic, a letter and/or email will be sent requesting the decedent's personal representative to participate in the study.

2) Cancer Care Support Group – While this is a general cancer care support group, the leader of the support group will select those persons who are seeking their services after losing someone to MBC. Inclusion and exclusion criteria will be provided

directly to the leader of the support group from the PI. If a cancer care support group

participant meets the eligibility criteria, a letter will be given to the participant for

self-selection.

3) Social Media Platforms – inclusion and exclusion criteria will be provided via a

social media announcement for the participant to self-select their eligibility.

Willing participants will then be provided a Qualtrics-specific link (Provo, UT) for the

survey and a telephone number for assistance over the phone with the survey, if needed. Any

information of the deceased MBC patient will not be collected prior to participation.

Upon completion of the survey, all of the DPRs will be able to voluntarily give their

consent for re-contacting to participate in the semi-structured telephone interview. To reduce any

chance of repeated survey or telephone interviews, unique data similarities will be reviewed.

The participant will choose if the QODD survey data will be collected using the Qualtrics

platform or over the telephone by the PI. If the QODD is conducted over the phone, the PI will

enter the survey results into the Qualtrics platform on behalf of the participant.

1.5.2.5 Variables

1.5.2.4.1 Defining the Independent Variable

For the quantitative portion of the mixed methods study, the independent variables will

include: 1) DPR characteristics (age, race, sex, education level, type of relationship to the

deceased, and length of relationship with the deceased); and 2) DPR-reported presence or

absence of poor quality EOL care indicators (more than one ED visit in the last 30 days of life,

more than one hospital admission in the last 30 days of life, at least one ICU admission in the last

30 days of life, death in the acute care setting, new chemotherapy regimen in the last 30 days of life, any chemotherapy administration in the last 14 days of life, and hospice care less than 3 days before death)

1.5.2.4.2 Defining the Dependent Variable

The quality of EOL care and the death experience will be determined from the perspective of the DPR through the QODD survey. This survey is a validated and reliable 25-item tool which evaluates six different domains including symptoms and personal care, preparation for death, moment of death, family, treatment preferences, and whole person concerns (Downey et al., 2010a). Each of the survey questions will target one of these six domains and assess: 1) frequency of an experience or event, and 2) the quality of that experience or event. The frequency of these experiences will be rated based on specific provided responses. The quality of these experiences will use an 11-point Likert scale rating from 0 (terrible) to 10 (almost perfect). If any participants who selected "I don't know" as their response, they were prompted to continue to the next question. The final 14 questions assess the participant's demographic and social background as well as relationship to the deceased.

1.5.2.6 Measures

Table 2: Variable, Measure. And Descriptive Statistics for Deceased Metastatic Breast Cancer (MBC) Patient Demographic, Social, Patient Health, Clinical, and EOL Care Indicators as provided by the Designated Personal Representative (DPR)

Variable	Measure	Type	Descriptive Statistics
Deceased Metastatic Breast Cancer (MBC) Patient Demographic, Social, Patient Health, Clinical, and EOL Care Indicators as provided by the Designated Personal Representative (DPR)			
Age at death (years)	Date of Death	Ratio	Mean, SD Median, IQR (if non-normal)
Race	Self-reported	Nominal	Frequency counts, percentages, mode, range
Sex	Self-reported	Dichotomous	Frequency counts, percentages
Marital Status	Self-reported	Nominal	Frequency counts,

			percentages, mode, range
Goals of Care Discussion	Yes/No	Dichotomous	Frequency counts, percentages
One or more ER visit in the last 30 days of life	Yes/No	Dichotomous	Frequency counts, percentages
One or more hospital admission in the last 30 days of life	Yes/No	Dichotomous	Frequency counts, percentages
ICU admission	Yes/No	Dichotomous	Frequency counts, percentages
Hospice care 3 days or less before death	Yes/No	Dichotomous	Frequency counts, percentages
New chemotherapy in the last 30 days of life	Yes/No	Dichotomous	Frequency counts, percentages
Any chemotherapy in the last 14 days of life	Yes/No	Dichotomous	Frequency counts, percentages
Death occurring in the acute care setting	Yes/No	Dichotomous	Frequency counts, percentages
Designated Personal Presentative Demographics			
Age (years)	Self-reported	Ratio	Mean, SD Median, IQR (if non-normal)
Race	Self-reported	Nominal	Frequency counts, percentages, mode, range
Sex	Self-reported	Nominal	Frequency counts, percentages, mode, range
Education	Self-reported	Ordinal (original) Nominal	Median, IQR Mode, Range
DPR Type	Self-reported	Ordinal (original) Nominal	Median, IQR Mode, Range
DPR Length of Relationship	Self-reported	Ratio	Mean, SD Median, IQR (if non-normal)
Designated Personal Presentative Survey			
QODD	25 question 10-point Likert scale/mixed questions	Highly ordinal – approx. Interval	Mean, SD Median, IQR (if non-normal

Table 3: Quality of Death and Dying Survey Questions

Quality of Death and Dying Survey (QODD)
During the last several days before your loved one passed:
1a. How often did your loved one appear to have his/her pain under control? (Circle one number)
1b. How would you rate this aspect of your loved one's dying experience? (Rated 0-10)

2a. How often did your loved one appear to have control over what was going on around him/her? (Circle one number)

2b. How would you rate this aspect of your loved one's dying experience? (Rated 0-10)

3a. How often was your loved one able to feed her/himself? (Circle one number)

3b. How would you rate this aspect of your loved one's dying experience? (Rated 0-10)

4a. How often did your loved one appear to breathe comfortably? (Circle one number)

4b. How would you rate this aspect of your loved one's dying experience? (Rated 0-10)

5a. How often did your loved one appear to feel at peace with dying? (Circle one number)

5b. How would you rate this aspect of your loved one's dying experience? (Rated 0-10)

6a. How often did your loved one appear to be unafraid of dying? (Circle one number)

6b. How would you rate this aspect of your loved one's dying experience? (Rated 0-10)

7a. How often did your loved one laugh and smile? (Circle one number)

7b. How would you rate this aspect of your loved one's dying experience? (Rated 0-10)

8a. How often did your loved one appear to keep his/her dignity and self-respect? (Circle one number)

8b. How would you rate this aspect of your loved one's dying experience? (Rated 0-10)

9a. How often did your loved one spend time with his/her family or friends? (Circle one number)

9b. How would you rate this aspect of your loved one's dying experience? (Rated 0-10)

10a. How often did your loved one spend time alone? (Circle one number)

10b. How would you rate this aspect of your loved one's dying experience? (Rated 0-10)

The following questions are answered with either a "Yes" or "No" based on whether your loved one did certain activities. Please rate the quality of that aspect of the dying experience. Again, we are asking you to focus on your loved one's last several days. During the last several days before your loved one passed:

11a. Was your loved one touched or hugged by his/her loved ones? (Circle one number))

11b. How would you rate this aspect of your loved one's dying experience? (Rated 0-10)

12a. Were all of your loved one's health care costs taken care of? (Circle one number)

12b. How would you rate this aspect of your loved one's dying experience? (Rated 0-10)

13a. Did your loved one say goodbye to loved ones? (Circle one number)

13b. How would you rate this aspect of your loved one's dying experience? (Rated 0-10)

14a. Did your loved one clear up any bad feelings with others? (Circle one number)

14b. How would you rate this aspect of your loved one's dying experience? (Rated 0-10)

15a. Did your loved one have one or more visits from a religious or spiritual advisor?

15b. How would you rate this aspect of your loved one's dying experience? (Rated 0-10)

16a. Did your loved one have a spiritual service or ceremony before his/her death?

16b. How would you rate this aspect of your loved one's dying experience? (Rated 0-10)

17a. Did your loved one receive a mechanical ventilator (respirator) to breathe for him/her?

17b. How would you rate this aspect of your loved one's dying experience? (Rated 0-10)

18a. Did your loved one receive dialysis for his/her kidneys? (Circle one number)

18b. How would you rate this aspect of your loved one's dying experience? (Rated 0-10)

19a. Did your loved one have his or her funeral arrangements in order prior to death?

19b. How would you rate this aspect of your loved one's dying experience? (Rated 0-10)

20a. Did your loved one discuss his or her wishes for end of life care with his/her doctor -- for example, resuscitation or intensive care? (Circle one number)

20b. How would you rate this aspect of your loved one's dying experience?

21a. Was anyone present at the moment of your loved one's death? (Circle one number)

21b. How would you rate this aspect of your loved one's death? (Circle one number)

22a. In the moment before your loved one's death, was he/she: (Circle one number)

22b. How would you rate this aspect of your loved one's death? (Rated 0-10)

23a. Overall, how would you rate the quality of your loved one's dying? (Rated 0-10)

24. Rate the care your loved one received from all doctors and other health care providers (including nurses, caseworkers, and other health care professionals) during the last several days of his or her life. (Rated 0-10)

25. Rate the care your loved one received from his or her doctor during the last several days of his or her life. (Rated 0-10)

In this section, we would like to ask a few questions about you and about your loved one.

1. When were you born?
2. When was your loved one born?
3. What is your gender?
4. What is your loved one's gender?
5. Approximately how many days was your loved one in the hospital? (If applicable)
6. Approximately how many days was your loved one in the intensive care unit (ICU)? (If applicable)
7. What is your ethnicity?
8. What is your race? (Circle all that apply)
9. What is the highest level of schooling you have completed? (Circle one number)
10. How are you related to your loved one? (Circle one number)
11. Did you live with your loved one? (Circle one number)
12. How long have you known your loved one?
13. Today's date is: (Please fill in today's date)
14. We would like to get feedback from you on how burdensome it was to complete this questionnaire. This information will help guide us in future research. Overall, how much of a burden on you was this questionnaire? (Circle one number)

1.5.2.7 Data Analysis Plan

1.5.2.7.1 Descriptive Statistics

Descriptive statistics, including mean, standard deviation, and range, will be used to summarize the MBC cohort sociodemographic characteristics, clinical factors, EOL care indicators, and QODD rating items and overall scores.

1.5.2.7.2 Data Screening Procedures

The data will be initially analyzed for accuracy through four separate stages: proofreading, computation of descriptive statistics, range checking, and contingency checking. This will help with understanding the distribution and if the sample itself, makes "sense." Additionally, if any data are found to be inconsistent or potentially entered in error, the PI will revisit the initial testing platform and compare answers.

1.5.2.7.3 Screening for Outliers

The data will then be examined for any outliers, as this can distort or inappropriately influence the summary and test statistics, cause type I and type II errors, and ultimately lead to results that may not be generalized after the findings are communicated. The detection of outliers will be based on the type of measurement and dimensionality. In the case of univariate outliers, an observation which is extreme on only one variable, it can be further subdivided into categorical and continuous variables. For categorical variables, frequency tables in SPSS will be conducted. For continuous variables, histograms, box plots, normality probability plots, and detrended normal probability plots will be conducted. In the case of multivariable outliers, a situation where there is an unusual combination of values on two or more variables, bivariate

plots between pairs of variables will be conducted. If any outliers in the data are found, the PI will decide whether to continue utilizing the observation in the sample, whether the scores should be modified, or whether the entire observation will be deleted.

1.5.2.7.4 Missing Data

The next component of the data screening procedures will be to initially analyze the data for any missing components. To fill-in any missing data, if possible, the research team will return to the original electronic medical record source. After attempting to fill all possible missing information gaps, the research team will discuss whether the missing information is vital to the analysis, whether inference is possible, and the amount, as well as distribution, of the missing data. The research team will then describe the pattern of missing data, as to whether it is related to single observation variables or longitudinal variables and whether it is missing at random (MAR) or completely at random (MCAR). Additionally, for longitudinal variables, the pattern of missing data will determine the most appropriate strategy for imputation.

1.5.2.7.5 Checking for Underlying Assumptions

The underlying assumptions of ordinal logistic regression will also be tested, which include 1) the dependent variable (i.e., the QODD survey score) is measured at the ordinal level, 2) one or more independent variables that are continuous, ordinal, or categorical, 3) no multicollinearity, and 4) proportional odds. Normality can be assessed using measures of skewness, kurtosis, the Shapiro-Wilks test, Q-Q plots, and histograms. To assess for multicollinearity, we will examine the variance inflation factor (VIF). If the estimated regression

coefficient value increases, the predictors are correlated. If the predictors are not correlated, then the VIF value will all be one.

1.5.2.7.6 Transformation of Data

Finally, data transformation can be utilized when the sample distribution is skewed or deviates from the normal distribution. The choice of data transformation (log, inverse, square-root) is dependent on the degree and direction of deviation. After any transformation is conducted, assumptions must be rechecked, category collapsing may be necessary, and the interpretation of results may have to be rescaled.

1.5.2.7.7 Data Analytics Procedure

To appropriately explore the relationship between variables, the objectives of the study need to be considered. Using descriptive statistics, the DPR cohort will be described according to their demographic and social factors. The QODD survey rating items and overall scores will also be presented descriptively. Using binary logistic regression, the association of demographic and social with the QODD survey scores will be used to examine the quality of care at the EOL for women deceased from MBC according to the perspective of their DPR.

1.5.2.8 Preliminary Results

Table 4 demonstrates the sociodemographic factors of the deceased MBC patients and their DPR (n=5).

Table 4: Preliminary Results for Sociodemographic Factors of Metastatic Breast Cancer Cohort and their Designated Personal Representative.

Sociodemographic Factors	MBC Cohort (n=5)
DPR Age (years)	50-71 years of age (*SD* 8.51), mean of 62.0 years of age
Patient Gender	100% Female (n=5)
DPR Gender	20% Female (n=1) 80% Male (n=4)
Hospital length (days) at the end-of-life	0-15 days (*SD* 6.27), 8.0 mean
ICU length (days) at the end-of-life	0% (n=0)
Ethnicity	20% European (n=1) 80% White (n=4)
Race	100% White (n=5)
Education	20% high school (n=1) 20% some college (n=1) 40% college (n=2) 20% graduate (n=1)
Relation	20% friend (n=1) 80% spouse (n=4)
Lived with	20% no (n=1) 80% yes (n=4)
Length of Relationship	7-47 years (*SD* 16.76), mean of 30.4

Table 5 shows the preliminary results found of five QODD survey responses. Responses for question 1 through 20 are scored on a 6-point Likert scale (none of the time, a little bit of the time, some of the time, a good bit of the time, most of the time, all of the time, and don't know) as well as a 0-10 scale (ranging terrible [0] to almost perfect [10]). Responses for question 21 through 47 are scored on a 3-4 point Likert scale (yes, no, and don't know) or (awake, asleep, in a coma or unconscious, and don't know) as well as a 0-10 scale (ranging terrible [0] to almost perfect [10]).

Table 5: Preliminary Results for Quality of Death and Dying Survey Results for the Designated Personal Representative

Number	Question	Responses
1a	How often did your loved one appear to have his/her pain under control?	40% - A little of time (n=2) 10% - A good bit of the time (n=1) 40% - All of the time (n=2)
1b	How would you rate this aspect of your	40% - score of 0-5 (n=2)

	loved one's dying experience?	60% - score of 6-10 (n=3)
2a	How often did your loved one appear to have control over what was going on around him/her	60% - a little bit of the time (n=3) 20% - some of the time (n=1) 20% - a good bit of the time (n=1)
2b	How would you rate this aspect of your loved one's dying experience?	80% - score of 0-5 (n=4) 20% - score of 6-10 (n=1)
3a	How often was your loved one able to feed her/himself?	40% - None of the time (n=2) 20% - A little of the time (n=1) 20% - A good bit of the time (n=1) 20% - All of the time (n=1)
3b	How would you rate this aspect of your loved one's dying experience?	60% - score of 0-5 (n=3) 40% - score of 6-10 (n=2)
4a	How often did your loved one appear to breathe comfortably?	40% - none of the time (n=2) 20% - a little bit of the time (n=1) 20% - a good bit of the time (n=1) 20% - most of the time (n=1)
4b	How would you rate this aspect of your loved one's dying experience?	60% - score of 0-5 (n=3) 40% - score of 6-10 (n=2)
5a	How often did your loved one appear to feel 6aat peace with dying?	20% - a little bit of the time (n=1) 40% - some of the time (n=2) 20% - a good bit of the time (n=1) 20% - all of the time (n=1)
5b	How would you rate this aspect of your loved one's dying experience?	80% - score of 0-5 (n=4) 20% - score of 6-10 (n=1)
6a	How often did your loved one appear to be unafraid of dying?	20% - none of the time (n=1) 20% - a little bit of the time (n=1) 20% - most of the time (n=1) 20% all of the time (n=1) 20% - unknown (n=1)
6b	How would you rate this aspect of your loved one's dying experience?	40% - score of 0-5 (n=2) 40% - score of 6-10 (n=2) 20% - unknown (n=1)
7a	How often did your loved one laugh and smile?	60% - none of the time (n=3) 20% - a little bit of the time (n=1) 20% - most of the time (n=1)
7b	How would you rate this aspect of your loved one's dying experience?	80% - score of 0-5 (n=4) 20% - score of 6-10 (n=1)
8a	How often did your loved one appear to keep his/her dignity and self-respect?	20% - a little of the time (n=1) 60% - a good bit of the time (n=3) 20% - most of the time (n=1)
8b	How would you rate this aspect of your	40% - score of 0-5 (n=2)

	loved one's dying experience?	60% - score of 6-10 (n=3)
9a	How often did your loved one spend time with his/her family or friends?	20% - a little bit of the time (n=1) 20% - a good bit of the time (n=1) 20% - most of the time (n=1) 40% - all of the time (n=2)
9b	How would you rate this aspect of your loved one's dying experience?	20% - score of 0-5 (n=1) 80% - score of 6-10 (n=4)
10a	How often did your loved one spend time alone?	40% - none of the time (n=2) 60% - a little of the time (n=3)
10b	How would you rate this aspect of your loved one's dying experience?	20% - score of 0-5 (n=1) 80% - score of 6-10 (n=4)
11a	Was your loved one touched or hugged by his/her loved ones?	100% - yes (n=5)
11b	How would you rate this aspect of your loved one's dying experience?	100% - score of 6-10 (n=5)
12a	Were all of your loved one's health care costs taken care of?	20% - no (n=1) 80% - yes (n=4)
12b	How would you rate this aspect of your loved one's dying experience?	100% - score of 6-10 (n=5)
13a	Did your loved one say goodbye to loved ones?	20% - don't know (n=1) 20% - no (n=1) 60% - yes (n=3)
13b	How would you rate this aspect of your loved one's dying experience?	40% - score of 0-5 (n=2) 40% - score of 6-10 (n=2) 20% - don't know (n=1)
14a	Did your loved one clear up any bad feelings with others?	40% - yes (n=2) 40% - no (n=2) 20% - don't know (n=1)
14b	How would you rate this aspect of your loved one's dying experience?	40% - score of 0-5 (n=2) 40% - score of 6-10 (n=2) 20% - don't know
15a	Did your loved one have one or more visits from a religious or spiritual advisor?	60% - yes (n=3) 40% - no (n=2)
15b	How would you rate this aspect of your loved one's dying experience?	20% - score of 0-5 (n=1) 80% - score of 6-10 (n=4)
16a	Did your loved one have a spiritual service or ceremony before his/her death?	60% - yes (n=3) 40% - no (n=2)
16b	How would you rate this aspect of your loved one's dying experience?	20% - score of 0-5 (n=1) 80% - score of 6-10 (n=4)
17a	Did your loved one receive a mechanical ventilator (respirator) to breathe for	100% - no (n=5)

	him/her?	
17b	How would you rate this aspect of your loved one's dying experience?	40% - score of 0-5 (n=2) 60% - score of 6-10 (n=3)
18a	Did your loved one receive dialysis for his/her kidneys?	20% - yes (n=1) 80% - no (n=4)
18b	How would you rate this aspect of your loved one's dying experience?	20% - score of 0-5 (n=1) 80% - score of 6-10 (n=4)
19a	Did your loved one have his or her funeral arrangements in order prior to death?	80% - yes (n=4) 20% - no (n=1)
19b	How would you rate this aspect of your loved one's dying experience?	40% - score of 0-5 (n=2) 60% - score of 6-10 (n=3)
20a	Did your loved one discuss his or her wishes for end of life care with his/her doctor -- for example, resuscitation or intensive care?	100% - yes (n=5)
20b	How would you rate this aspect of your loved one's dying experience?	40% - score of 0-5 (n=2) 60% - score of 6-10 (n=3)
21a	Was anyone present at the moment of your loved one's death?	100% - yes (n=5)
21b	How would you rate this aspect of your loved one's dying experience?	20% - score of 0-5 (n=1) 80% - score of 6-10 (n=4)
22a	In the moment before your loved one's death, was he/she:	20% - don't know (n=1) 80% - in a coma or unconscious (n=4)
22b	How would you rate this aspect of your loved one's dying experience?	20% - score of 0-5 (n=1) 60% - score of 6-10 (n=3) 20% - unknown (n=1)
23a	Overall, how would you rate the quality of your loved one's dying?	40% - score of 0-5 (n=2) 60% - score of 6-10 (n=3)
24	Rate the care your loved one received from all doctors and other health care providers (including nurses, caseworkers, and other health care professionals) during the last several days of his or her life.	100% - score of 6-10 (n=5)
25	Rate the care your loved one received from his or her doctor during the last several days of his or her life.	40% - score of 0-5 (n=2) 60% - score of 6-10 (n=4)

1.5.2.9 Discussion

These initial QODD survey data illustrates the varied perspective and uniqueness of the dying experience for women deceased from MBC. Continued survey participation as well as an

exploration of meanings behind the chosen answers through a qualitatively designed interview may give additional insight into the quality of EOL care and the dying experience.

1.5.3   Study 3: Qualitative Telephone Interviews

1.5.3.1 Study Design

Study 3 is the qualitative component of the sequential Quantitative-Qualitative mixed methods approach. For this qualitative portion, a semi-structured telephone interview will be conducted with the DPR. This interview will be used to understand more fully the DPR's perception and their perception of the patient's quality of EOL and death experience. The mixed-methods approach is vital to allow for a deep examination into the meaning and experiences behind the QODD survey responses. Moreover, in turn, the QODD survey responses will help to tailor telephone interview questions. For example, if the DPR had reported in their QODD survey that the patient experienced mechanical ventilation at the end-of-life, additional questions regarding their intensive care stay would be conducted. Collectively, this will provide a tailored, yet novel view of EOL care quality and the death experience for women with MBC, according to the perspective of the DPR.

1.5.3.2 Study Setting

The telephone interviews will be conducted over the phone with the PI. Participants will be recruited from four groups: 1) a southwestern Pennsylvania designated cancer center outpatient clinic including MBC patients deceased from November 2016 to October 2020, 2) a local Pittsburgh cancer support group for DPRs, and 3) two social media group platforms with an MBC emphasis.

1.5.3.3 Study Sample

1.5.3.3.1 Subject Inclusion, Exclusion, and Data Collection Protocol

For patients from the southwestern Pennsylvania designated cancer center outpatient clinic identified for the database of Aim 1 and those who passed away after the retrospective chart review was completed until October 2020, the EHR will be searched to identify the "next of kin" or the "designated personal representative." This can include their identified partner, spouse, family, or support person. The exclusion criteria are any individuals age<18 years of age. Once the DPR participants are identified, a letter will be sent to the physical address found in the patient's EHR. In the letter, there will be an explanation of the research study and a unique study Qualtrics link. In case the physical address does not connect with the DPR, an email to the DPR will also be sent.

For DPR participants who are recruited from the support group or social media platform groups, the inclusion criteria are 1) self-reported DPR (whether a partner, spouse, family, or support person) for women diagnosed with and deceased from MBC; and 2) age>18 years. The exclusion criteria are any individuals age<18 years of age.

Regardless of recruitment locations, the DPR participants can use the provided Qualtrics-specific link to either read the consent form and agree to participate in the QODD survey online or decline to participate. They can also call the provided research team number to take the survey with assistance over the phone from the PI. If the DPR chooses to complete the QODD survey with the Qualtrics platform, consent is completed electronically. If the DPR chooses to complete the QODD over the phone with the PI, the QODD survey consent is conducted over the phone.

Once the QODD survey is completed online, there is an optional qualitative interview that the DPR can participate in. It is at this point that the DPR provides their telephone number

and information regarding the best day and time to be reached. At the appointed time for the telephone interview, the PI will then consent each DPR participant over the phone, and verbal consent is received before the interview is conducted. If the DPR chooses to complete the QODD survey over the phone with the PI, the qualitative interview consent form is also reviewed and verbal consent is received before proceeding with the interview.

1.5.3.3.2 Sample Size Justification

Constant comparative analysis for semi-structured interviews will be conducted with a suggested sample size between 6-12 persons of each desired grouping of the QODD questionnaire results (those who rated their loved one as having a poor-quality death and those who rated their loved one as having a high-quality death) or until data saturation has been reached, that is, no new information is being uncovered (Creswell, John W. 1998; Malterud et al., 2016; Turner-Bowker et al., 2018; Vasileiou et al., 2018)

1.5.3.4 Methods

The script utilized for the study will be created and streamlined with assistance from study design and EOL care experts, as well as the MBC literature. The telephone interviews will be conducted by the PI with assistance from experienced faculty members as needed.

On the selected day, an approximately 30-minute semi-structured telephone interview will be conducted with the DPR. The DPR will be given open ended questions regarding their perspectives on support provided from the healthcare team and community support system; unique burdens or stressors associated with the diagnosis, treatment, and EOL care; past experiences with EOL care; effect on daily activities and priorities; and experiences around any

EOL care or GOC discussions that took place. Interviews will be audio recorded, transcribed by the PI or official transcription service, and verified.

1.5.3.5 Data Analysis Plan

1.5.1.6.1 Preparation for Analysis

To establish preliminary impressions and ideas, the entire set of qualitative data will be read. This will be done prior to any initial coding.

1.5.1.6.2 Data Reduction

While the text will be examined for keywords and terms (i.e., goals of care, end-of-life care, poor death, etc.), it will not be the sole criteria used for collapsing or eliminating data. Moreover, it would also be considered valuable if these topics were not found in the interview transcript as it may carry a meaningful discovery.

1.5.1.6.3 Primary Coding and Establishment of the Codebook

After preliminary interviews were conducted, an initial codebook was developed regarding the DPR's perceptions of EOL care, components of their loved one's metastatic diagnosis and treatment, financial burdens, and bereavement care.

After all interviews are conducted and completed, the principal investigator (PI) will be performing the transcription of the interview tapes and subsequent analysis of the transcripts. The research team will discuss and anonymize participants as early as possible. Using NVivo12 software (version 12), content from the interviews will be coded per content analysis by the PI, an expert clinical nurse. Primary coding for ten percent of the DPR cohort will be conducted by

two coders independently. These coders will discuss and achieve consensus on the codes, with

revisions being done as needed. As additional interviews are conducted, additional codes may be

added. The finalized codebook will include definitions and sub-codes.

1.5.1.6.4 Planned Data Interpretation

Common themes will be identified and recorded in the respondent's own words. Using

constant comparative techniques, codes will be clustered into themes, and themes will be

clustered into categories (Creswell, John W. ; Poth, 1998). Qualitative findings will be

disseminated separately from the quantitative portion of the study to adequately give depth and

breadth to the interview process and answers provided by the participants.

1.5.3.6 Preliminary Results – Presented at Comps and Overview

After the qualitative interview, each participant (n=5) was asked to recall the presence or

absence of these EOL care indicators. These results are displayed in Table 6.

Table 6: Preliminary Results for End-of-Life Care Indicators of the Metastatic Breast Cancer Cohort according to the Designated Personal Representative.

EOL Care Indicators	MBC Cohort (n=5)
New chemotherapy 30 days prior to death	40% no (n=2) 40% yes (n=2) 20% unknown (n=1)
Any chemotherapy 14 days prior to death	80% no (n= 4) 20% unknown (n=1)
One or more ER visit in the last 30 days	20% no (n=1) 60% yes (n=3) 20% unknown (n=1)
One or more hospital admission in the last 30 days	40% no (n=2) 60% yes (n=3)
ICU admission in the last 30 days	80% no (n=4) 20% unknown (n=1)
Hospice 3 days or less before death	40% no (n=2) 60% yes (n=3)
Death in the acute care setting	20% no (n=1) 80% yes (n=4)

1.5.3.7 Discussion – Presented at Comps and Overview

1.5.4 Study 4: Integration of Findings from Project 1, 2. and 3

1.5.4.1 Purpose

Develop a care guideline around the implementation strategies of quality care based on results of Aims 1, 2, and 3.

1.5.4.2 Design

The design will be a qualitative content analysis of results from studies 1,2, and 3 and of the qualitative findings according to specific, interviewed groups (i.e., RN, social workers, registered dieticians, and APPs).

1.5.4.3 Setting

The setting will be at a southwestern Pennsylvania cancer clinic of a National Cancer Institute (NCI) designated cancer center.

1.5.4.4 Sample

The sample will include five different clinician groups within the southwestern Pennsylvania cancer clinic: 1) clinicians who participate in an MBC-focused care meeting (i.e., MBC oncology RNs, licensed social workers, registered dieticians, nurse practitioners, and palliative care team members), 2) direct-care APPs, 3) RN staff members, 4) MBC patient navigators, and 5) treating oncologists.

1.5.4.5 Methods

After the findings from studies 1, 2, and 3 are integrated and best practice guidelines and implementation strategies are developed, the PI will attend an established meeting with each of the designated clinician groups separately (i.e., MBC-focused care meeting, APP meeting, RN staff meeting, and patient navigators meeting).

At each of the meetings, the PI will present a summary of the findings from studies 1, 2, and 3 alongside the current practice guidelines. After the presentation is conducted, the PI will then direct focused questions towards the clinicians regarding their opinion of the presented guidelines and implementation strategies, feasibility of practices, and actual integration within their current clinic practices. Furthermore, clinicians will provide their opinion regarding any facilitators, burdens, or barriers to the provided suggestions of previous research.

1.5.4.6 Analysis

From these interviews, common themes will be identified according to the different clinician groups and recorded in the respondent's own words. Using constant comparative techniques, codes will be clustered into themes, and themes will be clustered into categories (Creswell, John W. ; Poth, 1998). From these categories, the developed best practice guidelines will be modified for applicability within the MBC patient care context.

Table 7: Dissertation Study Timeline

	Fall Semester 2020	Spring Semester 2021	Summer Semester 2021	
STUDY TIMELINE				
IRB approval	Completed			
Comprehensive Exams		Scheduled for 3/8/2021		
Specific Aim 1	Completed			
Specific Aim 2				
Specific Aim 3				
Specific Aim 4				
Dissertation Manuscript and Presentation Preparation				
Dissertation Defense				
Dissemination of Results				

1.7   PROTECTION OF HUMAN SUBHECTS

1.7.1   Human Subjects Involvement, Characteristics, and Design

Human Subjects Involvement. This is not a clinical trial, but a two-part mixed-methods study. The first component is a chart review using electronic medical record (EHR) data to collect the designated personal representative's contact information. To locate the appropriate DPR timeframe, all patients, from whom the DPR is derived, that are included in the chart review interval (11/2016-10/2020, totaling n=177), were deceased from metastatic breast cancer, and treated at the southwestern Pennsylvania designated cancer center outpatient clinic. The only data extracted from the patient's chart for this portion of the study will include certain patient demographics for verification purposes (i.e., name, date of birth, and date of death) and DPR

demographics (i.e., name, address, and email). Only data de-identified are recorded in the research study files and identified by study ID only. For those DPR participants who are recruited from the cancer care support group or social media platform groups, no previous information will be collected due to its understood anonymity. Any extracted EHR data will be obtained by the same principal investigator and each DPR participant will be assigned a study ID linking these additional data to the same participants' previously collected data and will reside on the same secure server.

Characteristics of the population. The patient population in the study is consistent with the characteristics of patients treated at a southwestern Pennsylvania designated cancer center outpatient clinic over the study period of 11/2016-10/2020. The racial and ethnic characteristics of the subject population reflects the monitored patient population during the above study periods. The DPR cohort will be derived from the previously mentioned patient population. In addition, the DPR cohort will include those participants who have also taken part in the cancer care support groups and the social media platform groups.

Inclusion criteria: Entry criteria into the study is composed of three different participant populations and set of criteria. The first population was composed of a convenience sample of patients deceased from metastatic breast cancer (MBC), treated at the southwestern Pennsylvania designated cancer center outpatient clinic, and age >18 years of age. The DPR cohort will be derived from the previously mentioned patient population (as noted in the electronic medical record). Finally, the second and third DPR participant cohorts are those who have also taken part in the cancer care support groups and the social media platform groups. No special classes of participants in the retrospective study interval, the patient's designated personal representative, or MBC-specific provider were excluded.

Exclusion criteria: Children were not included as participants in the study and the entry criterion was set at > 18 years of age. The southwestern Pennsylvania designated cancer center outpatient clinic is an adult outpatient care clinic. Any patients age < 18 years or treated outside of the clinic were not admitted to the study's deceased patient cohort and eliminated from the analyses. For the patient's DPR, any participants <18 years of age were not included in the advanced cancer care survey or semi-structured interviews.

Inclusion of special classes: Inclusion of special classes: No special classes of patient in the retrospective study interval, (women of childbearing age, pregnant women, prisoners, and institutionalized individual) were excluded. Children were not included as participants in the parent study and the entry criterion was set at > 18 years of age. The southwestern Pennsylvania designated cancer center outpatient clinic is an adult outpatient care facility. Any patients age < 18 years who were admitted to the study unit cohort spanning 11/2016 and 10/2020 were noted and their data eliminated from the analyses.

1.7.2 Source of Data

Description of Data

The southwestern Pennsylvania designated cancer center outpatient clinic uses EPIC Electronic Medical Records as their outpatient data collection program. All patient and DPR characteristics are located within the southwestern Pennsylvania designated cancer center outpatient clinic EPIC Medical Records. No other pre-survey or pre-interview data was collected on those DPR participants who were recruited from the cancer care support group or social medial platform groups.

Data Access

Data are stored at the University of Pittsburgh School of Nursing secure server in password protected files. After DPR participants complete the survey and telephone interview, a unique study ID was provided and the participant information was de-identified. Only key personnel associated with this research will have access to the information.

1.7.3 Potential Risks and Adequate Protection Against Risk

Recruitment and Informed Consent

The clinical and demographic data for all deceased patents in the study interval were obtained and continue to be evaluated under IRB approval. Use of these data for an expanded research agenda, using the previously collected data, augmented by unstructured clinical data, in a slightly different manner to answer a different research question, will be supported under a separate IRB-approved protocol.

Justification for Waiver of Informed Consent

Informed consent was waived for all data collection in the initial study, because: 1) no protected health information was recorded; and 2) no identifiers were recorded.

Protections Against Risk.

Only de-identified study data are stored on password protected study computers that reside within the University of Pittsburgh Schools of Nursing and the PI. The only potential risk could be breach of confidentiality based on access to the study code linkage files. This risk is low and retained by the principal investigator from the study. No official study files contain MRNs or other Protected Health Information (PHI), as they are only assigned study IDs as identifiers.

1.7.4   Potential Benefits of the Proposed Research to Human Subjects

There are no direct benefits to the patients or the DPRs. However, with the information gathered, it may provide an improved quality of EOL care to future women diagnosed with metastatic breast cancer and their designated personal representative.

1.7.4.1 Importance of the Knowledge to be Gained

MBC treatment course and EOL care is heterogenic due to socioeconomic factors, disease subtypes, provider differences, and patient and family preferences. This proposed study is to describe the common variables, unique palliation needs, and potential predictors that are associated with those who experienced a "poor quality of EOL care" according to established quality indicators at EOL and the perspectives of the DPRs of women deceased from MBC. Laying this important preliminary groundwork first, we will then develop a predictive model for patients most at risk for poor quality of death and the optimal timing for integrating a goals of care discussion so as to maintain patient-directed goal concordant care.

1.7.5   Data and Safety Monitoring Plan

The principal investigator and mentor, Dr. Rosenzweig, will be responsible for the ongoing evaluation of the progress of the research study. They will ensure that no patient Personal Health Information has entered the study database. During monthly meetings, Dr. Rosenzweig will review progression of the study, data integrity, and preliminary results when available. Any breaches in data safety will be investigated and reported to the IRB. The primary investigator is responsible for reporting back the findings to Dr. Rosenzweig.

To summarize and reiterate: There is no risk of physical harm to the patient by being in

the study. The only risk to the patient would be a remote breach of confidentiality. However, we have minimized the opportunity for that to occur. Once the clinical data elements are collected, it is maintained in a research file identified only by study ID. For the patient's DPR, there may be some emotional discomfort or stress. Supportive care staff and referrals will be integrated at each step within the study to ensure there is minimization of risk.

Ultimately, this dissertation study will refocus what it means to give high quality and meaningful EOL care to the MBC population. This process will evaluate current EOL care, evolving treatment practices, and seek to capture the patient experience and DPR's voices. Assimilating these areas together will allow for future implementation of a fully integrated quality care guideline process.

2.0   CHANGES TO THE PROPOSED PROJECT

2.1   RESEARCH DESIGN AND METHODS

2.1.1   AIM 1: Data Analysis Procedures – Sample Size Justification

The purpose of this research study is to describe the quality of EOL care and death experience for women diagnosed and deceased from MBC. Each one of the categories of interest (i.e., the patient's demographic, social, patient health, clinical, and EOL care indicators) must be considered.

With a retrospective chart review study design, there have been many suggestions as to what would constitute an appropriate sample size. However there is not a universally agreed upon set of guidelines for this type of study design (Vassar & Matthew, 2013). Furthermore, for a logistic regression analysis, there is also variability. One study has suggested a minimum of 500 participants, however, they note that those studies with sample sizes less than 500, may also be sufficient for associations with a medium to large effect size (Bujang et al., 2018). Another study has suggested obtaining a certain number of events per variable (EPV) to calculate sample size (Gearing et al., 2006; van Smeden et al., 2019). For example, if nine independent variables were used in relation to one dependent variable, this would require a minimum study sample of 90 participants. However, this criterion, as some have suggested, may be insufficient for

prediction modeling. Finally, recent retrospective chart review studies, regardless of whether a pre-determined guidelines were discussed, has presented data results with sample sizes ranging from 95 to 786 (Abou Dagher et al., 2017; Artico et al., 2018; Mohty et al., 2019; SooHoo et al., 2018; Srouji et al., 2021).

For the purposes of this study, as a convenience sample is being used, there is a pre-determined set number of patients that are deceased from MBC within the desired timeframe. Therefore, using the recommended g*power analysis program for two-tailed logistic regression, the power analysis will be calculated using an effect size of 0.3, alpha of 0.05, and sample size of 167 participants (Vassar & Matthew, 2013). With this calculation, the power analysis is 0.748.

2.1.2 AIM 2: Quality of Death and Dying (QODD) Survey

2.1.2.1 Study Sample – Sample Size

The study sample for the QODD survey will be driven by the data saturation of the telephone interviews, conducted in AIM 3. The QODD survey responses and scores will be linked with each of the interviewed DPR participants.

2.1.2.2 Data Analysis Procedures

Descriptive statistics, including mean, standard deviation, and range, will be used to summarize the MBC cohort sociodemographic characteristics, clinical factors, EOL care indicators, and QODD rating items and overall scores.

2.1.3   AIM 3: Qualitative Interview

2.1.3.1 Study Sample - Sampling Procedures

Constant comparative analysis for semi-structured interviews will be conducted with a suggested sample size between 10-20 persons, or until data saturation has been reached, that is, no new information is being uncovered (Creswell, John W. 1998; Malterud et al., 2016; Turner-Bowker et al., 2018; Vasileiou et al., 2018). After each semi-structured interview has been conducted, their QODD survey responses will be linked.

2.1.3.2 Data Analysis Plan - Coding

After the first five interviews are conducted, an initial codebook will be developed with two independent coders. These coders will discuss and achieve consensus on the codes regarding the DPR's perceptions of EOL care, components of their loved one's metastatic diagnosis, treatment, financial burdens, and bereavement care, with revisions being done as needed.

After all interviews are conducted and completed, the PI will be performing the transcription of the interview tapes and subsequent analysis of the transcripts. The research team will discuss and anonymize participants as early as possible. Using NVivo12 software (version 12), content from the interviews will be coded per constant comparative method by the PI, an expert clinical nurse. Primary coding for ten percent of the DPR cohort will be conducted by two coders independently. As additional interviews are conducted, additional codes may be added. The two independent coders will then code two additional interviews in the middle of the participant sample as well as at the end. They will discuss their independent results, and achieve consensus, with arbitration if required. The finalized codebook will include definitions and sub-codes.

2.1.4 AIM 4: Mixed Methods Study

2.1.4.1 Sample

The sample will include six different clinician groups within the southwestern Pennsylvania cancer clinic: 1) RN staff members, 2) licensed social workers, 3) registered dieticians, 4) direct-care APPs, 5) palliative care team members, and 6) MBC patient navigators.

2.1.4.2 Methods

Each participant who took part in a telephone interview will be categorized based on their QODD survey response regarding whether or not their loved one was able to share their EOL care wishes with their physician. The responses could either be, "yes," "no," or "I don't know." After each participant is categorized according to these responses, they will then be further subdivided into how they rated this experience. The experience could be rated from 0-10, with 0 meaning "terrible" up to 10, meaning "almost perfect." Participants will be divided into three categories based on this score, placed into the following groupings: scores 0-4, scores 5-7, and scores 8-10. The PI will then examine the participant's telephone interview responses regarding EOL care wishes with their survey response scores.

After the interview responses are appropriately categorized, the PI will attend an established meeting to present a summary of the findings from studies 1, 2, and 3 alongside the current practice guidelines. After the presentation is conducted, the PI will then direct focused questions towards the clinicians regarding their opinion of the presented guidelines and potential of implementation strategies, feasibility of practices, and actual integration within their current clinic practices. Furthermore, clinicians will provide their opinion regarding any facilitators or barriers to the provided suggestions of previous research.

2.1.4.3 Analysis

From these interviews, common themes will be identified according to the different clinician groups and recorded in the respondent's own words. Using constant comparative techniques, codes will be clustered into themes, and themes will be clustered into categories (Creswell, John W. ; Poth, 1998). From these categories, the developed best practice guidelines will be modified for applicability within the MBC patient care context.

3.0 DISSERTATION MANUSCRIPT 1A: "THE QUALITY OF END-OF-LIFE CARE FOR WOMEN DECEASED FROM METASTATIC BREAST CANCER"[1]

3.1 ABSTRACT

This retrospective chart review study was conducted to explore the association between the patient's demographic, social, patient health, and clinical factors at diagnosis with the utilization of poor-quality end-of-life care indicators for a comprehensive understanding in the current trends in EOL care quality. This study adds to the existing literature in emphasizing the complexities of MBC disease and treatment management.

Background: Providing high quality care at the end-of-life (EOL) is essential for patients diagnosed with an advanced illness and limited life expectancy. Specific indicators of poor quality EOL care include curative-focused treatments administered close to death, limited utilization of hospice care, preventable acute care use, and ultimately, care that is not in concordance with patient goals and treatment decisions (Assari et al., 2019; Khandelwal et al., 2017). Although MBC is responsive to an ever-increasing range of chemotherapy and targeted therapies, it is still a progressive, life ending disease with an average range of survival between

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24 to 52 months (Laohavinij et al., 2017; Santa-Maria & Gradishar, 2015). Therefore, it is important for clinicians to better understand these disease-related and external factors that place a patient at high risk for poor-quality EOL care.

Objective: The aims of this study were to 1) describe a cohort of women recently deceased from MBC; 2) examine the incidence of poor quality EOL care indicators among women deceased from MBC; and 3) explore the association of poor quality EOL care indicators according to key demographic, social, patient health, and clinical factors among women recently deceased from MBC.

Methods: The study design was a retrospective chart review of data compiled from the electronic health records (EHR) of patients deceased from MBC between November 1, 2016, through November 30, 2019. Data extracted included date of birth, date of metastatic diagnosis, insurance status, tumor subtype, presence of comorbidities, and poor quality EOL care indicators. Race, spiritual affiliations, zip code, marital status, and employment status were self-reported upon intake into the clinic, included in the EHR, and only changed upon the patient's request. The last listed zip code was utilized to calculate the Neighborhood Deprivation Index (NDI).

Results: A total of 167 women were included in this analysis. Across the sample, age at diagnosis ranged from 29.6 to 89.6 years, mean 55.3 years (*SD* 11.73). The majority of the sample, (n=132, 79%), were under the age of 65 years at the time of diagnosis. Most women were White, reported a spiritual affiliation, and were either married or partnered. All were insured, with a majority being publicly insured through Medicare or a Pennsylvania-based program for coverage of breast cancer diagnosis and treatment (n=119, 84.4%). Over 25% of the MBC cohort had one or more mental health comorbidities and over 50% of the MBC cohort had

one or more physical comorbidities. There was a racial survival disparity as from MBC diagnosis, White women had an overall survival of 41.2 months (3.4 years), while Black women had an overall survival of 19 months (1.6 years).

Of the demographic factors, increasing age at MBC diagnosis was correlated to a higher incidence of ICU admissions 30 days prior to death (p=0.03) and trended towards significance with more than one hospital stay 30 days prior to death (p=0.06). Endorsement of spiritual affiliation increased the likelihood of experiencing one or more ER visits (4.2 times), hospital admissions (1.9 times), ICU admissions (3.9 times) in the last 30 days of life and was associated with death occurring in the acute care setting (3.1 times). Patients from neighborhoods of more deprivation were more likely to experience delayed hospice referrals (p=0.02). Married patients were 4.1 times more likely to receive any chemotherapy in the last 14 days of life. The presence of even a physical (p=0.001) or mental health (p=0.002) comorbidity were associated with delayed hospice referrals.

Conclusion: While a patient may have experienced one or more poor quality EOL care indicators, it is challenging to label their EOL care and death as "poor." Ultimately, poor quality EOL care indicators may not measure the complexity of today's metastatic cancer treatment or capture the patient's and their DPR's hopes and expectations.

Keywords: End-of-Life, Quality of Care, Metastatic Breast Cancer, Sociodemographic Factors, Clinical Factors, Palliative Care, Good Death

3.2   INTRODUCTION

Providing high quality care at the end-of-life (EOL) is essential for patients diagnosed with an advanced illness and limited life expectancy. Specific indicators of poor quality EOL care include curative-focused treatments administered close to death, limited utilization of hospice care, preventable acute care use, and ultimately, care that is not in accordance with patient goals and treatment decisions (Assari et al., 2019; Khandelwal et al., 2017).

Cancer is highly prevalent and the second leading cause of death in the United States (Miller et al., 2016). Breast cancer is the second most common cancer among women in the United States (Miller et al., 2016). Of the 3.5 million women in the United States with a history of breast cancer, one-third will eventually develop metastatic disease (Mariotto et al., 2017a; Miller et al., 2016). Cancer symptoms and the unique side effects of cancer treatment (e.g., chemotherapy, radiation, immunotherapy, etc.) can impact the complexity of care at death due to the specific cancer diagnosis, disease-associated burdens, and severity of treatment toxicity (Aldridge & Bradley, 2017; Earle et al., 2003). Survival prognostications are complex and often overly optimistic for MBC. Multiple factors are considered, including tumor subtype, MBC treatment choices, gene expression profiles, and type of organ-specific relapses (Alečković et al., 2019; Laohavinij et al., 2017; Partridge et al., 2016; Santa-Maria & Gradishar, 2015). Ultimately, it is challenging to know when treatments will no longer result in meaningful improvement and instead of offering therapeutic benefit, become unhelpful and unwanted. Although MBC is responsive to an ever-increasing range of chemotherapy and targeted therapies, it is still a progressive, life ending disease with an average range of survival between 24 to 52 months (Laohavinij et al., 2017; Santa-Maria & Gradishar, 2015).

Therefore, it is important for clinicians to better understand these disease-related and external factors that place a patient at high risk for poor-quality EOL care. Along with multiple tumor and disease factors, demographic, social, patient health, and clinical factors can impact the quality of EOL care. These factors include, age, (Dialla et al., 2015; Falchook et al., 2017; Miesfeldt et al., 2012) race, (Abdollah et al., 2015; Miesfeldt et al., 2012) neighborhood deprivation, (Dialla et al., 2015; Zhang et al., 2018) marital status, (Dinh et al., 2018; Li et al., 2015; Qiu et al., 2016) spiritual affiliation, (Hong & Cagle, 2019; LeBaron et al., 2015; Rohani et al., 2015) presence or absence of comorbidities, (Fu et al., 2015; Sarfati et al., 2016; Wachterman et al., 2016) and tumor subtype (Laohavinij et al., 2017; Partridge et al., 2016; Plevritis et al., 2018). As the disease progresses and EOL care is required, these factors will have an increasingly important influence on the preference and consistency of goal concordant care, method of treatment delivery, and death context (Khandelwal et al., 2017; Parr et al., 2010b). Competing personal needs, prioritizing of resources (e.g. time, money, transportation, distance from care), and geographically associated barriers can also affect access to care and availability of providers, thereby diminishing the quality of MBC care (Brown et al., 2018; Chang et al., 2014; Lin et al., 2015).

Theoretical Framework

Emanuel & Emanuel's Framework for a Good Death served as the basis for this study (Emanuel & Emanuel, 1998). The Framework for a Good Death was created to better conceptualize the three factors influencing the death experience: 1) fixed characteristics of the patient (e.g., demographic, social, patient health, and clinical factors), 2) modifiable dimensions of the patient's experience (e.g., physical symptoms, hopes and expectations, etc.), and 3) care-system interventions (e.g., family and friend interventions, social interventions, etc.). The

outcome of the framework, the overall death experience, is multifaceted. Adapting this model, we included important sociodemographic and clinical factors relevant to MBC patients and their death experience. These factors, available from administrative data, included age at MBC diagnosis, race, spiritual affiliations, neighborhood deprivation, marital status, employment and insurance status, number of comorbidities, and tumor subtype. The specific indicators of poor quality EOL care in patients with cancer were derived from the literature and include: 1) potentially preventable medical encounters in the last month of life, 2) delayed hospice referrals in those nearing the EOL, and 3) aggressive chemotherapy utilization in the last month of life. These were further dissected into seven measurable EOL care indicators: new chemotherapy received in the last 30 days of life, any chemotherapy received in the last 14 days of life, more than one emergency room visit in the last 30 days of life, more than one hospital stay during the last 30 days of life, admitted to the intensive care unit in the last 30 days of life, hospice enrollment only three days or less prior to death, and death occurring in the acute care setting (Earle et al., 2003). The authors acknowledge that not all stakeholders involved in the discernment of EOL care helped to form these indicators (Earle et al., 2003).

While the measures of EOL quality cancer care have been measured in several populations, to our knowledge, this will be the first study to explicitly measure quality EOL care indicators in conjunction with a comprehensive range of patient-related factors within the MBC population. Examining the intersection of advanced cancer care, patient-related factors, and specific tumor characteristics are important to consider within our current understanding of the resources, concerns, and burdens currently experienced by the MBC population. Ultimately, exploring the unique combination of patient-related factors and tumor subtype characteristics may help to identify future patients most at risk for poor quality EOL care and allow for targeted,

individualized interventions. Therefore, the aims of this study were to 1) describe a cohort of women recently deceased from MBC; 2) examine the incidence of poor quality EOL care indicators among women deceased from MBC; and 3) explore the association of poor quality EOL care indicators according to key demographic, social, patient health, and clinical factors among women recently deceased from MBC.

3.3 METHOD

Study Design, Sample, and Setting

Design: The study design was a retrospective chart review of data compiled from the electronic health records (EHR) of patients deceased from MBC between November 1, 2016, through November 30, 2019. Data extraction occurred between June 2019 and March 2020. The chart review dates selected were concurrent with the start of an interdisciplinary *Metastatic Breast Cancer Program of Care,* a weekly patient review meeting that began in October 2016 (Reiser et al., 2019b). These review meetings identify and link patients to the necessary supportive care services (e.g., palliative care, financial care, or social work). This study was approved by the University of Pittsburgh Institutional Review Board (IRB) prior to initiation of data collection.

Sample and Setting: Inclusion criteria were women: 1) 18 years of age or older; 2) diagnosed with MBC, including de novo diagnosis (metastatic at diagnosis) or diagnosis of MBC after a previous diagnosis of stage I-III breast cancer; 3) received oncology treatment at a southwest Pennsylvania academic clinic; and 4) death occurring November 1, 2016, through November 30, 2019. Exclusion criteria included patients who were: 1) male and 2) whose

treatment course was not directed at the cancer clinic. Male MBC patients were not included as this study sought to specifically capture the quality of EOL care for female patients. Patients who came for a consult or second opinion only were also excluded due to limited availability of MBC treatment information.

Data Source/Data Collection

All data collection was performed by the primary author. Any data from the medical record requiring clarifications were discussed with a senior member of the research team, who is also a clinician in the cancer center. To verify and assess accuracy of the data, 10% of the sample were randomly selected and reviewed by another registered nurse (Vassar & Matthew, 2013). Any identified discrepancies or uncertainties were discussed and consensus was reached. Data screening procedures were conducted to initially analyze the data for any missing components or conflicts. To complete any missing data, the research team returned to the original EHR source. After attempting to fill all possible missing information gaps, the research team decided that date of death and date of metastatic disease diagnosis were vital to the analysis, and, if either was missing, the case was excluded.

Demographic and Social Factors. Data extracted included date of birth, date of metastatic diagnosis, insurance status, and presence of comorbidities. Where appropriate, the data were regularly verified and updated. Race, spiritual affiliations, zip code, marital status, and employment status were self-reported upon intake into the clinic, included in the EHR, and only changed upon the patient's request.

The last listed zip code was utilized to calculate the Neighborhood Deprivation Index (NDI). NDI is a tool developed to measure five broad sociodemographic domains linked with health outcomes: income/poverty, education, employment, housing, and occupation (Messer et

al., n.d.). The NDI is a useful tool to capture a geographical context as it incorporates not only employment and insurance information, but also education, housing, and income data. The NDI is also a more comprehensive way to measure socioeconomic status (SES) than income alone. Using census data, each geographical area (arranged by zip code) is given a score ranging from 0-100 with higher numbers indicating greater SES deficiencies. It should be noted that as a cross-sectional study, the extracted zip code for this cohort was during MBC treatment; however cross-sectional zip codes are a sufficiently reliable indicator of exposure to neighborhood deprivation within a 1-3 year time frame (Knighton, 2018).

Patient Health Factors. Comorbidities, including mental health conditions were chronic, diagnosed conditions extracted from the provider-driven EHR "diagnosis list." Physical and mental health comorbidities were extracted separately. In this study, transient conditions that were treated and resolved were not considered a comorbidity, such as hypoxia or anemia due to acute blood loss. Mental health symptoms (such as feeling anxious, 'blue', or stressed) that were mentioned in clinical notes but not included in the EHR "diagnosis list," were also not included. Comorbidities were coded as either present (diagnosed with one or more) or not present.

Clinical Factors. Tumor subtype was determined from tumor pathology reports and verified by consistency in prescribed treatments and consistency in clinical notes. Any discrepancies between pathology reports and clinical notes were reviewed by an experienced member of the clinical team and resolved. Tumor subtypes, included for descriptive purposes, were estrogen receptor (ER) status (negative or positive) and human epidermal growth factor receptor 2 (HER2) status (negative or positive). The analysis did not include progesterone receptor (PR) status as care is primarily dependent on the ER and HER2 status (Nahid Nafissi, 2016; Rossi et al., 2015).

Indicators of Poor Quality EOL Care. Poor quality EOL cancer care has been described as care that is overly "aggressive" in nature (Earle et al., 2003, 2005; A. K. Smith et al., 2009). Occurrence of these indicators were found through a protocolized review of both EHR and meeting notes from regular supportive care meetings. Each poor quality EOL indicator was dichotomously coded.

3.4   STATISTICAL ANALYSIS

All statistical analyses were conducted using IBM SPSS Statistics software (version 26) (IBM Corp., n.d.). Data screening procedures were completed, including data screening for any missing components, computation of descriptive statistics, range checking, and contingency checking. To fill-in any missing data, the research team first returned to the original EHR source. After attempting to fill all possible missing information gaps, the distribution of missing data were assessed.

Descriptive statistics, such as mean, standard deviation, and range, were used to summarize the MBC cohort sociodemographic characteristics, clinical factors, and EOL care indicators. Binary logistic regression was performed to assess the relationship between sociodemographic and clinical factors with poor quality of end-of-life care indicators. Statistical significance was considered $p < 0.05$, two-tailed. The underlying assumptions for binary logistic regression were tested including, a single binary dependent variable, one or more independent variables, independence of observations with mutually exclusive categories, sufficient sample size in each dependent variable or independent category, linearity of any continuous independent

variables with the logit transformation of the dependent variable, no serious multicollinearity, and absence of outliers or influential points.

Normality was assessed using measures of skewness, kurtosis, the Shapiro-Wilks test, Q-Q plots, and histograms. Independence was assessed by using scatterplots. The variable of interest was presence or absence of any poor-quality EOL care indicators. Linearity of "Age at MBC diagnosis" and "Neighborhood Deprivation Index" with respect to the logit of the dependent variable was assessed using the Box-Tidwell approach. All continuous, independent variables met this assumption. The length of overall survival had one case with a standardized residual value of 2.770 standard deviations. As the case was not influential, it was kept in the analysis. High multicollinearity was found between employment status, insurance status, and marital status. Therefore, insurance status and employment status were removed from the binary logistic regression model with partner status retained as a predictor variable. Finally, due to insufficient category size and reflective of patient demographics at the clinic, one patient with self-reported race other than Black or White was removed, allowing a dichotomized racial variable.

3.5   RESULTS

Eight women were excluded due to vital missing data. The results of the descriptive analysis for this study are reported in Table 8. A total of 167 women were included in this analysis.

Table 8: Sample Characteristics and Demographics (N=167)

Characteristics	Mean±SD or n(%)	Range
Length of Survival	3.12 years ± 3.31	32 days -16.7 years
Age at MBC diagnosis (years)	55.3 ± 11.73	29.6-89.6
Age at death (years)	57.6 ± 11.69	32.6-90

Race
  Black
  White
	
	24 (14.4%)
	143 (85.6%)
		NA

Spiritual Affiliations (yes)	148 (88.6%)	NA
National Deprivation Index[A]	61.71 ± 24.97	7-97
Marital Status[B] (married/partnered)	81 (57.4%)	NA
Employed[B] (yes)	64 (45.4%)	NA

Insurance[B] (yes)
  Privately Insured
  Publicly Insured
    Medicare Advantage Plans
    Medicare
	141 (100%)
	22 (15.6%)
	
	43 (30.5%)
	76 (53.9%)
		NA

Comorbidities
  Mental health comorbidities
  (MHC) (no. of conditions)
    0
    1 or more
 	
  Physical comorbidities (PCM)
  (no. of conditions)
    0
    1 or more
	
	123 (72.8%)
	44 (26.3%)
	
	73 (43.2%)
	94 (56.3%)
		0-5
		
		0-9

Tumor Subtype
  ER+/HER2+
  ER+/HER2-
  ER-/HER2-
  ER-/HER2+
	
	23 (13.8%)
	76 (45.5%)
	53 (31.7%)
	14 (8.4%)
		NA

NA Not Applicable
A: High NDI scores indicate a higher prevalence of deprivation.
B: n=141

Descriptive Statistics Results

Demographic, Social, Patient Health, and Clinical Factors. Across the sample, age at diagnosis ranged from 29.6 to 89.6 years, mean 55.3 years (*SD* 11.73). The majority of the sample, (n=132, 79%), were under the age of 65 years at the time of diagnosis. Most women were White, reported a spiritual affiliation, and were either married or partnered. All were insured, with a majority being publicly insured through Medicare or a Pennsylvania-based program for coverage of breast cancer diagnosis and treatment (n=119, 84.4%). Over 25% of the MBC cohort had one or more mental health comorbidities and over 50% of the MBC cohort had one or more physical comorbidities. There was a racial survival disparity from the time of MBC diagnosis, White women had an overall survival of 41.2 months (3.4 years), while Black women had an overall survival of 19 months (1.6 years).

End-of-Life Care Indicators Table 9 displays the frequency of poor quality EOL care indicators. The most prevalent poor quality EOL care indicators were: 1) hospice enrollment three days or less prior to death, 2) admitted to the ICU in the last 30 days of life, and 3) death occurring in the acute care setting.

Table 9: Frequency of End-of-Life Care Indicators (N=167)

End-of-Life Care Indicators	Total Sample n (%)
New chemotherapy in the last 30 days of life	13 (7.8)
Any chemotherapy in the last 14 days of life	23 (13.8)
More than one ER visit in the last 30 days of life	37 (22.2)
More than one hospital stay during the last 30 days of life	43 (25.7)
Admitted to the Intensive Care Unit in the last 30 days of life	49 (29.3)
Hospice enrollment only three days or less prior to death	97 (58.1)
Death occurred in the acute care setting	61 (36.5)

Hospice enrollment occurring three days or less prior to death was 58.1% (n=97). The mean days for hospice admission prior to death were 18.2 days and a median of 7 days. Looking further at hospice care for this MBC cohort, 44.9% (n=75) did not participate in any hospice services and 13.2% (n=22) participated in hospice for 2 days or less.

Binary Logistic Regression Results

The relationships between each poor quality EOL care indicator and the demographic, social, patient health, and clinical factors are displayed in Table 10.

Table 10: Multivariable Binary Logistic Regression Results comparing Demographic, Social, Patient Health, and Clinical Factors with each of the Poor Quality End-of-Life Care Indicators (N=167)

Demographic, Social, Patient Health, and Clinical Factors (reference category)	New Chemotherapy in the last 30 days of life		Any chemotherapy in the last 14 days of life		One or more ER visit in the last 30 days of life		More than one hospital stay during the last 30 days of life		Admitted to the ICU in the last 30 days of life		Hospice enrollment at least three days or less prior to death		Death occurred in the acute care setting	
	Adjusted Odds Ratio	95% CI	Adjusted Odds Ratio	95% CI	Adjusted Odds Ratio	95% CI	Adjusted Odds Ratio	95% CI	Adjusted Odds Ratio	95% CI	Adjusted Odds Ratio	95% CI	Adjusted Odds Ratio	95% CI
Demographic Factors														
Age at MBC diagnosis (Increasing)	0.957	0.894-1.024	0.962	0.909-1.018	0.981	0.940-1.025	0.960	0.920-1.002	0.959	0.923-0.997	0.971	0.935-1.008	0.984	0.949-1.020
Race (Black)	4.839	0.865-27.082	1.612	0.273-9.510	1.339	0.319-5.619	1.617	0.423-6.181	1.674	0.508-5.516	1.075	0.323-3.581	1.492	0.474-4.694
Social Factors														
Spiritual Affiliation (Yes)	0.823	0.132-5.111	1.003	0.164-6.150	4.234	0.509-35.256	1.853	0.459-7.481	3.873	0.790-18.995	0.994	0.282-3.491	3.121	0.782-12.460
Neighborhood Deprivation Index (Increasing)	1.009	0.978-1.040	1.006	0.982-1.031	0.985	0.967-1.002	0.987	0.970-1.004	1.007	0.991-1.024	1.020	1.003-1.037	1.012	0.996-1.028
Marital Status (Married)	1.627	0.360-7.343	4.110	0.984-17.167	1.007	0.386-2.624	1.025	0.400-2.623	1.126	0.480-2.640	1.813	0.787-4.176	1.382	0.618-3.088
Patient Health Factors														
Mental Health Comorbidities (Present)	0.279	0.028-2.785	0.591	0.135-2.594	0.776	0.262-2.302	0.399	0.123-1.294	0.510	0.199-1.389	0.210	0.076-0.576	0.483	0.191-1.223
Physical Comorbidities (Present)	1.010	0.244-4.172	2.208	0.625-7.797	1.913	0.712-5.137	1.083	0.443-2.643	1.164	0.501-2.704	4.558	1.900-10.937	2.186	0.961-4972
Clinical Factors														
ER Status (Negative)	1.302	0.318-5.329	1.296	0.398-4.217	0.836	0.338-2.069	0.519	0.212-1.267	0.479	0.208-1.104	0.537	0.244-1.182	0.777	0.362-1.668
HER2 Status (Negative)	0.486	0.098-2.401	0.510	0.124-2.093	0.501	0.168-1.497	0.668	0.244-1.832	1.700	0.610-4.737	2.407	0.905-6.402	0.916	0.351-2.390

Demographic Factors. Of the demographic factors, increasing age at MBC diagnosis was correlated to a higher incidence of ICU admissions 30 days prior to death (p=0.03) and trended towards significance with more than one hospital stay 30 days prior to death (p=0.06). Black women were also more likely to experience each poor quality EOL care indicator as compared with White women, including new chemotherapy in the last 30 days of life, any chemotherapy in the last 14 days of life, one or more ER visit in the last 30 days of life, more than one hospital stay in the last 30 days of life, admittance to the ICU in the last 30 days of life, hospice enrollment at least three days or less prior to death, and death occurring in the acute care setting. For example, Black women were 4.8 times more likely to receive new chemotherapy in the last 30 days of life than White women.

Social Factors. Endorsement of spiritual affiliation increased the likelihood of experiencing one or more ER visits (4.2 times), hospital admissions (1.9 times), ICU admissions (3.9 times) in the last 30 days of life and was associated with death occurring in the acute care setting (3.1 times). Patients from neighborhoods of more deprivation were more likely to experience delayed hospice referrals (p=0.02). Married patients were 4.1 times more likely to receive any chemotherapy in the last 14 days of life.

Patient Health and Clinical Factors. The presence of even a physical (p=0.001) or mental health (p=0.002) comorbidity were associated with delayed hospice referrals. For clinical factors, patients with negative ER status tended to receive both new chemotherapies in the last 30 days of life and any chemotherapy in the last 14 days of life.

3.6 DISCUSSION

While researchers and clinicians alike have sought to improve the quality of EOL cancer care, there is still a great deal to understand regarding how to provide the most tailored and optimal care. Due to disease and subsequent treatment variability, there are often fluctuating and competing care needs unique to the MBC population. These needs must be recognized with care approaches customized in response to a wholistic patient assessment.

To describe our MBC cohort of women in context, we compared it to the MBC population at large. Nationwide breast cancer statistics show that our MBC cohort has a lower average age at diagnosis and a higher percentage of the ER-/HER2- subtype (31.7% vs. 12%) (American Cancer Society, 2019). We recognize that this comparison is made between those diagnosed with MBC versus our population of those deceased from MBC, which may explain some of the variation in percentages. The 5-year survival rate for this MBC cohort is 19.9% with the national MBC population average at 27% (*Cancer Statistics Review, 1975-2016 - SEER Statistics*, n.d.). Racial disparities were present both across the nation and in this MBC cohort (DeSantis et al., 2017). Black women continue to be younger at the age of MBC diagnosis, have a higher percentage of MBC diagnosis with aggressive subtypes, and a shorter overall length of survival. For example, White women had an average survival of 41.2 months and Black women had an overall survival of 19 months. The startling gap in overall length of survival in this MBC cohort depicts some of the harsh realities that exist in the current healthcare system, social climate, and geographical context.

Similar to other cancer populations, this MBC cohort experienced a higher prevalence of poor quality EOL care indicators, including admittance to the ICU in the last 30 days of life and death occurring in the acute care setting (Falchook et al., 2017). However, unlike other cancer

populations, this MBC cohort also had a higher prevalence of hospice enrollment only three days or less prior to death. The grouping of these poor quality EOL care indicators could be the result of a "domino" effect. For example, for patients who are accustomed to going to the "next therapy," they may not perceive a particular acute situation as truly the EOL. Therefore, when the severity of symptoms increases at the EOL, an ER visit with subsequent ICU admittance occurs because patients and families expect that they will recover. Regardless of previous conversations with their provider have occurred previously, the patient's expectation is often that of survival and receiving additional treatment options after discharge. Additionally, the patient or family may not yet be accepting of the finality of their diagnosis and wish to pursue aggressive treatment measures. Therefore, it is plausible that these poor quality EOL care indicators may occur in clusters and represent a patient population with many treatment possibilities who are now unaccustomed to no further therapeutic options. Even if an EOL discussion occurred, it was in the theoretical future.

The utilization of both palliative care (80.8%, n=135) and social work (83.8%, n=140) was the standard of care for this MBC cohort, with the majority of the sample receiving these services. Yet, 64.1% (n=107) of the sample still experienced one or more poor quality EOL care indicators. While goals of care discussions were not examined in this study, it is understood that these discussion sessions can result in better EOL care quality (Haun et al., 2017; O'Connor et al., 2015; Park et al., 2018). However, these discussions are not on a strict protocol, conducted at irregular intervals, and its initiation is often based on provider judgement (Kaldjian, Lauris, MD, 2019; Matsuoka et al., 2018; Piggott et al., 2019).

In addition to examining the prevalence of poor quality EOL care indicators, we also evaluated characteristics among patients most likely to experience these poor quality EOL care

indicators. Within this MBC cohort, these characteristics included age at MBC diagnosis, marital or partner status, and estrogen-targeted subtypes. By further examining these characteristics, it may provide additional insight into the complex nature of EOL care.

Age at MBC diagnosis is important for EOL care considerations. The approach to treatment and care goals can be meaningfully different and requires a careful dialogue of age-specific care needs. Younger patients may still be reliant on their parents or completely independent with young children. Older patients may be living with their adult children or caring for dependent spouses or older children. Additionally, the effects of age can greatly impact the development of additional comorbidities, and may in fact, limit treatment choices.

Marital or partner status has been shown to play an important role, serving as a proxy for more global social support, improving care outcomes, helping the patient to understand the illness, offering a supportive role outside of the clinic, and providing medical and treatment decision-making support (Inverso et al., 2015; Li et al., 2015; Qiu et al., 2016; Wright et al., 2008). However, in this MBC cohort, there was a greater likelihood of experiencing all of the poor quality EOL care indicators when married or partnered. In part, this may be due to the patient or spouse/partner not understanding prognosis severity, difficulty or denial of the grief process, and/or lack of communication with healthcare team (Dionne-Odom et al., 2017, 2019; Ornstein et al., 2016).

There are an increasing number of estrogen-targeted treatments for metastatic breast cancer. However, with already limited treatment options, ER negative subtypes were more likely to utilize new chemotherapy in the last 30 days of life and any chemotherapy in the last 14 days of life. For this group, it may be important to consider the symptom side effects, number of disease progressions, changes in treatment type, and ultimately, the patient's treatment goals.

With the expectation of life prolonging treatment, patients, with estrogen negative MBC, alongside their loved ones, may not seriously consider the possibility of EOL.

Ultimately, while a patient may have experienced one or more poor quality EOL care indicators, we did not label their EOL care and death as "poor." Yet, others have attempted to describe it in a dualistic nature. For example, a "good death" has been described as one with no pain and excellent symptom management, (Kehl, 2006; Meier et al., 2016; Yun et al., 2018) trust in care providers, (Holdsworth, 2015; Kehl, 2006; Meier et al., 2016) adequate preparation for death, (Holdsworth, 2015; Kehl, 2006) perception of a high quality of life prior to death, (Meier et al., 2016) the patient's perception of leaving a legacy, (Kehl, 2006; Meier et al., 2016; Yun et al., 2018) patient-directed decision making, (Kehl, 2006; Meier et al., 2016) completion of goals, (Holdsworth, 2015; Meier et al., 2016; Yun et al., 2018) and affirmation of the whole person (Kehl, 2006; Meier et al., 2016). Conversely, a "poor death" has been described as one with a lack of preparation on the part of the patient and/or family, (Costello, 2006; Karanth et al., 2018; LeBaron et al., 2015) unexpected location or manner, (Costello, 2006; Karanth et al., 2018) aggressive medical interventions close to death, (Costello, 2006) lack of dignity and respect surrounding the death experience, (Costello, 2006) and failure to complete religious rites (Costello, 2006; LeBaron et al., 2015). However, while these descriptions may be accurate to some, it does not take into account the EOL care complexities and individualistic experiences that occur (Kehl, 2006). Ultimately, poor quality EOL care indicators do not measure the complexity of today's metastatic cancer treatment or capture the patient's expectation and hope for another treatment option. Therefore, we must examine more closely these poor quality EOL care indicators for applicability, completeness, and accuracy in the MBC population according to specific demographics.

3.7   CONCLUSION

3.7.1   Strengths and Limitations

This study has several strengths. The data utilized for the study, from 2016-2019, reflects the current standard of treatment and experience of poor quality EOL care indicators. Additionally, this cohort represents a wide range of demographic, social, patient health, and clinical factors. There are important considerations to this study. Retrospective data collection, while allowing for a discrete current cohort of deceased patients, does limit the collection of desired variables. The sociodemographic factors were collected at the diagnosis of MBC and may not have been regularly nor systematically reviewed throughout the years of MBC treatment. This study's cohort is limited to a single outpatient women's health clinic over a specific time interval with a smaller sample size, limiting generalizability. However, the sample is populated from a four state region and is reflective of the geographical location of the primary treatment center. Additionally, the poor quality EOL care indicators for MBC patients will need to be assessed and validated on other EHR data sets. Lastly, the patient and family voice is important. We must assess these "poor" quality indicators from the point of view of patients with this disease and of family/support persons after their loved one's death.

3.7.2   Conclusion

With this initial study, we sought to further understand the process of objectively measuring the quality of end-of-life care and its unique burden on the MBC population. Our goal is to prospectively identify influential characteristics that are meaningful at the EOL. The

application of discovering and applying these variables in the MBC population may be useful to future MBC patient navigation and in adjusting the provider's awareness of patients at risk for poor quality EOL care. To achieve quality EOL care, treatment discussions and iterative goal revision must occur over time, well before death is imminent, recognizing that the content of such discussions is complex and will vary depending upon the perceived and actual needs of the patient and their family.

4.0 DISSERTATION MANUSCRIPT 1B: PREVALENCE, PATTERN, AND PROBABILITY FOR GOALS OF CARE DISCUSSIONS AMONGST WOMEN DIAGNOSED WITH METASTATIC BREAST CANCER[2]

4.1 ABSTRACT

Background: High quality advanced cancer care includes goals of care (GOC) discussions, and should be tailored according to clinical diagnosis, patient characteristics, and in concordance with patient's goals. Metastatic breast cancer (MBC) and treatment has heterogeneity according to subtype which makes the timing of initiating and continuing GOC discussions challenging. With an ever-increasing array of therapy, women with advanced stage disease are unique survivors in that they receive relatively aggressive cancer care to not only palliative symptoms but extend survival time. It is the purpose of this paper to explore the prevalence, pattern, and likelihood of having a GOC discussion according to key tumor, demographic, social, and clinical factors.

Methods: The was a retrospective chart review, compiled from the electronic health records (EHR) of patients deceased from MBC between November 1, 2016, through November

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30, 2019. Extracted data included date of birth, metastatic diagnosis date, insurance status, comorbidities, tumor subtype, and presence or absence of advance care planning (ACP), palliative care, social work, or a goals of care (GOC) discussion. Race, spiritual affiliations, zip code (to calculate Neighborhood Deprivation Index (NDI)), marital status, and employment status were self-reported upon intake into the clinic.

Results: The majority of the sample were younger than 65 years at MBC diagnosis (n=132, 79%), White (n=143, 85.6%), spiritually affiliated (n=148, 88.6%), either married or partnered (n=81, 57.4%), insured (n=141,100%; program in Pennsylvania guarantees breast cancer treatment coverage), and participated with palliative care (n=133, 79.6%), social work (n=140, 83.8%), or advance care planning (n=85, 51.2%). On average, Black women survived 19 months while White women survived 41.2 months. The timing of GOC discussions for Black women occurred late in the illness as compared with White women. A higher percentage of Black women (n=3, 14.2%) had their first GOC discussion three days or less before death as compared to White women (n=7, 5.6%).

A total of 464 individual GOC discussions occurred. While 87.4% (n=146) of the MBC cohort had a documented GOC discussion, they were not consistently conducted. Overall, the majority of the MBC cohort (n=99, 59.3%) had between 1 to 3 GOC discussions with 45.9% (n=67) having their first documented GOC discussion 3 months or less before death, and 12.6% (n=21) never having a documented GOC discussion at all. In total, the primary oncologist accounted for 29.3% of the GOC discussions. Utilization of palliative care (p<0.001) and social work (p=0.035) were both independently associated with increasing the probability of having a GOC discussion.

Conclusion: Advanced stage cancers are treated, at times relatively aggressively, to extend survival time instead of merely offering palliation. This new paradigm of survivorship requires thoughtful integration of GOC conversations. Describing the current status of GOC discussions among a cohort of women deceased from MBC highlights the patients most vulnerable to having a GOC discussion avoided or delayed. These identified vulnerabilities will indicate where targeted interventions can be implemented in the future.

Keywords: Metastatic Breast Cancer, Terminal Illness, Goals of Care

4.2   INTRODUCTION

Metastatic breast cancer (MBC) is a heterogenic disease with multiple treatment algorithms and a wide prognostic range due to tumor subtype. MBC care reflects a new paradigm in cancer treatment. With an ever-increasing array of therapy, women with advanced stage disease are unique survivors in that they receive relatively aggressive cancer care to not only palliative symptoms but extend survival time. This new paradigm of extending survival rather than "keeping people comfortable" delays both the initiation and continuation of GOC discussions (Glare et al., 2003). Regardless of treatment improvements, however, MBC is still a chronic, progressive life-ending disease. Therefore, to meet the needs of these unique survivors, clinicians must ensure that end-of-life (EOL) care is still aligned with patient wishes. In order to prevent the futile and inappropriate utilization of aggressive care measures, these discussions must be normatively integrated along the continuum of care (Haun et al., 2017; Mack, Cronin, Keating, et al., 2012; Wright et al., 2008).

High quality advanced cancer care includes goals of care (GOC) discussions at diagnosis and with each treatment progression, and should be tailored according to clinical diagnosis, and patient characteristics (Levit et al., 2013). This can be especially challenging considering ethnic, cultural, and geographical context (Mack et al., 2010). Advanced cancer GOC discussions go beyond merely treatment discussions. Therefore, for the purposes of this paper, GOC discussions are defined as any discussion between patient and provider used to clarify prognosis, treatment options, expectations, EOL care planning, and patient wishes for future direction of care (Levit et al., 2013; Schulman-Green et al., 2018). According to the American Society of Clinical Oncology consensus guideline, GOC discussions should be completed at diagnosis, with each relapse or progression, change in treatment approach, and at patient/family request and be

iteratively revised throughout care for clarity in disease prognosis, treatment concerns, mitigating symptom burden, and preparation for end of-life (EOL) care (Gilligan et al., 2017). Ideally, these discussions should be provided by the treating oncologist, with the integration of available palliative and other supportive services, for true, integrated oncologic care (Schulman-Green et al., 2018).

Therefore, the aims of this study are to examine: 1) the current prevalence and pattern of GOC discussions for a cohort of women deceased from MBC; and 2) the potential influence of sociodemographic, patient health, clinical or supportive care factors on the presence of GOC discussions. Understanding the current status of GOC discussions in an MBC cohort may illustrate future patients most vulnerable to having delayed or absent GOC discussions. These identified vulnerabilities will then indicate where future targeted interventions can be implemented.

4.3 METHODS

Study Design, Sample, and Setting

Design: The study design was a retrospective chart review, compiled from the electronic health records (EHR) of patients deceased from MBC between November 1, 2016, through November 30, 2019. The review dates were concurrent with initiation of an interdisciplinary Metastatic Breast Cancer Program of Care beginning in October 2016 (Reiser et al., 2019b). These weekly meetings identified and linked patients to supportive care services (e.g., palliative care, financial care, support groups, and social work).

Sample and Setting: Inclusion criteria were women: 1) aged 18 years or older; 2) diagnosed with MBC; 3) received primary oncology treatment at a southwest Pennsylvania academic clinic; and 4) death occurring between November 1, 2016, and November 30, 2019. Exclusion criteria included patients who were: 1) male and 2) whose treatment course was not directed at the cancer clinic. Male MBC patients were not included because their incidence is rare and results are not generalizable to the largely female cohort, as this study sought to specifically capture the GOC discussions for female patients.

Data Source/Data Collection

Approval was received from the University of Pittsburgh Institutional Review Board. All data collection was performed by the first author. Verification and accuracy assessments of the data were conducted. Ten percent of the sample abstraction was randomly selected and double coded by an additional registered nurse using preestablished codes. Identified discrepancies or uncertainties were discussed with a senior member of the research team, who is also a clinician in the cancer center, and consensus was reached.

Demographic and Social Factors

Extracted data included date of birth, metastatic diagnosis date, insurance status, and comorbidities. Race, spiritual affiliations, zip code (to calculate Neighborhood Deprivation Index (NDI)), marital status, and employment status were self-reported upon intake into the clinic. Where appropriate, the data were regularly verified and updated.

Patient Health Factors

Comorbidities, including mental health conditions, were chronic, diagnosed conditions extracted from the provider-driven EHR "diagnosis list." Transient conditions were not

considered a comorbidity. Physical and mental health comorbidities were extracted separately. Comorbidities were coded as either present (diagnosed with one or more) or not present.

Clinical Factors

Tumor subtype was determined from tumor pathology reports and verified by prescribed treatments and consistency in clinical notes. Tumor subtypes, included for descriptive purposes, were estrogen receptor (ER) status (negative or positive) and human epidermal growth factor receptor 2 (HER2) status (negative or positive).

Supportive Care Factors

If one clinical note was present from either palliative care or social work, it was considered present. Advance care planning (ACP) was dichotomized as either present or absent regardless of ACP type (e.g., Physician orders for Life-Sustaining Treatment (POLST), Living Will, or "yes, but not presently on file")

GOC discussions were obtained from clinical notes and other electronic documentation (e.g., phone/email communication) from the date of MBC diagnosis to date of death. Each communication point was categorized as a GOC discussion if prognosis or treatment updates occurred with a concurrent discussion about patient's treatment preferences or future wishes. Clinical notes that included only the phrase "goals of care," were not automatically included. Two variables were collected. The first was if any GOC discussion occurred and by whom. The second was if a quality standard of more than one GOC discussion occurred with the treating oncologist over the course of the MBC illness.

Statistical Analysis

All statistical analyses were conducted using IBM SPSS Statistics software (version 26). Data screening procedures were completed. MBC cohort characteristics were summarized using

descriptive statistics and binary logistic regression was used to characterize associations through the adjusted odds ratio, confidence interval, and p-value. The underlying assumptions for binary logistic regression were tested. Due to multicollinearity with the neighborhood deprivation index, insurance status and employment status were removed from the analysis. Statistical significance was considered $p < 0.05$.

4.4 RESULTS

Sample demographics and characteristics for the overall cohort (N=167) are summarized in Table 11.

Table 11: Sample Demographic and Clinical Characteristics (N=167)

Characteristics	Mean±SD or n(%)	Range
Age at metastatic diagnosis (years)	55.3 ± 11.73	29.6-89.6
Tumor Subtype ER+/HER2+ ER+/HER2- ER-/HER2- ER-/HER2+	23 (13.8%) 76 (45.5%) 53 (31.7%) 14 (8.4%)	NA

Comorbidities
  Mental health comorbidities
  (no. of conditions)
    0
    1 or more
 	
  Physical comorbidities
  (no. of conditions)
    0
    1 or more
	0.7365 ± 0.442
	
	123 (72.8%)
	44 (26.3%)
	
	0.437 ± 0.498
	
	73 (43.2%)
	94 (56.3%)
		0-5
		
		0-9

Length of Survival (years)
  Black
  White
	3.12 years ± 3.31
	19 months
	41.2 months
		32 days -16.7 years

Race
  Black
  White
	24 (14.4%)
	143 (85.6%)
		NA

Spiritual Affiliations (yes)	148 (88.6%)	NA
National Deprivation Index[A]	61.71 ± 24.97	7-97
Marital Status[B] (married/partnered)	81 (57.4%)	NA
Employed[B] (yes)	64 (45.4%)	NA

Insurance[B] (yes)
  Privately Insured
  Publicly Insured
    Medicare Advantage Plans
    Medicare
	141 (100%)
	22 (15.6%)
	
	43 (30.5%)
	76 (53.9%)
		NA

Palliative Care (yes)	133 (79.6%)	1-36 appointments
Social Work (yes)	140 (83.8%)	1-27 appointments

Advanced Care Planning (yes)[C]
  POLST
  Living Will
  Yes, but ACP type not on file
  No
	85 (51.2%)
	28 (16.8%)
	18 (10.8%)
	39 (23.5%)
	81 (48.8%)
		NA

Goals of Care Discussions (yes)	2.00 median with a 2.00 IQR	1-12 discussions
Ideal Goals of Care Discussions (yes)[D]	34 (20.4%)	NA

NA = Not Applicable
A: High NDI scores indicate a higher prevalence of deprivation.
B: n=141
C: n=166
D: More than one goals of care discussion was conducted by the primary Oncologist during the disease course.

The majority of the sample were younger than 65 years at MBC diagnosis (n=132, 79%), White (n=143, 85.6%), spiritually affiliated (n=148, 88.6%), either married or partnered (n=81, 57.4%), insured (n=141,100%; program in Pennsylvania guarantees breast cancer treatment coverage), and participated with palliative care (n=133, 79.6%), social work (n=140, 83.8%), or advance care planning (n=85, 51.2%). On average, Black women survived 19 months while White women survived 41.2 months.

A total of 464 individual GOC discussions occurred. While 87.4% (n=146) of the MBC cohort had a documented GOC discussion, they were not consistently conducted. Overall, the majority of the MBC cohort (n=99, 59.3%) had between 1 to 3 GOC discussions with 45.9% (n=67) having their first documented GOC discussion 3 months or less before death, and 12.6% (n=21) never having a documented GOC discussion at all. Those who did not receive any GOC discussions (n=21, 12.6%), had no sociodemographic or patient health commonalities. The vast majority did not participate in palliative care (n=15, 71.4%) or social work (n=10, 47.6%) assistance. In total, the primary oncologist accounted for 29.3% of the GOC discussions. The binary logistic regression results of the probability of having any GOC discussion are reported in Table 12.

Table 12: Multivariable Binary Logistic Regression Results of the Association of Demographic, Social, Patient Health, Clinical, and Supportive Care Factors with the Probability of having a GOC Discussion (N=167)

Demographic, Social, Patient Health, Clinical, and Supportive Care Factors	Goals of Care Discussions (Yes)		
	Adjusted Odds Ratio (AOR)	95% CI[A] for AOR	P-value
Demographic Factors			
Age at metastatic diagnosis (<65 years Or >65 years)	0.929	0.851-1.013	p=0.095
Age at metastatic diagnosis (years)	1.036	0.113-9.473	p=0.975
Race (Black)	0.755	0.124-4.580	p=0.760
Social Factors			
Religious Affiliation (Yes)	5.534	0.552-55.470	p=0.146
Marital Status (Married)	0.362	0.046-2.876	p=0.337
Neighborhood Deprivation Index	1.015	0.979-1.051	p=0.424
Patient Health Factors			
Mental Health Comorbidities (Present)	0.350	0.028-4.349	p=0.414
Physical Comorbidities (Present)	0.617	0.065-5.858	p=0.674
Clinical Factors			
ER Status (Negative)	0.723	0.118-4.445	p=0.726
HER2 Status (Negative)	0.537	0.034-8.582	p=0.660
Supportive Care Factors			
Palliative Care (Yes)	54.148	6.651-440.818	p<0.001
Social Work (Yes)	7.730	1.159-51.579	p=0.035
Advanced Care Planning (Yes)	4.081	0.532-21.322	p=0.176

A: Confidence Interval

Utilization of palliative care (p<0.001) and social work (p=0.035) were both independently associated with increasing the probability of having a GOC discussion. No other demographic, social, patient, clinical, or supportive care interventions were associated overall.

For Black women, the odds of having a GOC discussion were higher than White women. However, it does not illustrate the entire patient context. The timing of GOC discussions for Black women occurred late in the illness as compared with White women. A higher percentage of Black women (n=3, 14.2%) had their first, documented GOC discussion three days or less before death as compared to White women (n=7, 5.6%).

A high percentage of patients had their first GOC discussion in the acute care setting. To provide context for these GOC discussions and EOL care, 25.7% had more than one hospital stay (n=43) and 29.3% were admitted to the Intensive Care Unit (ICU) (n=49) within 30 days of death. Additionally, more than a third of the MBC cohort died in the acute care setting (36.5%, n=61). Of the total discussions, 40.1% were conducted with an inpatient physician (not the treating oncologist); 17% were with an outpatient, non-oncology physician; 7.3% were with

advance practice practitioners (APP) or registered nurses; 3.2% were with a social worker; 2.8% were with an emergency medicine physician or ICU physician; and 0.2% were with the chaplaincy team. Overall, palliative care providers, engaged in 200 discussions (43.1%); 71% were inpatient conversations, and 29% were in the outpatient setting.

4.5   DISCUSSION

Early and frequent GOC conversations have been shown to offer goal-consistent care, reduced financial burden, less aggressive medical measures near the EOL, higher quality EOL care, and positive family outcomes (Bernacki & Block, 2014). These considerations have not been updated in view of the array of treatment options now available for patients with late-stage cancers. Patients are using acute care resources close to death illustrating the need for consistent and seamless palliative care across all care timepoints and settings. Due to the variability in length of survival and disease progression rates, initial and continued GOC discussions should be an integral aspect of care for women at specific times and more as needed among women diagnosed with MBC. However, despite the documented integration of palliative care and social work for over 80% of this MBC population, GOC discussions still remain a quality gap among this cohort. More needs to be explored regarding the patients who received no GOC discussion. It is important to know if the patient has declined these conversations, if they died unexpectedly, or if nothing in their disease course triggered a GOC discussion.

4.6   CONCLUSION

4.6.1   Strengths and Limitations

There are several strengths to this study. The detailed examination of every clinical care note comprehensively captured the complexity of a GOC discussion. Additionally, while treated at one facility, this cohort is from four surrounding states which gives variability in patient, social, and geographical context. We acknowledge the possibility that GOC discussions took place without being documented. In order to ensure optimal survivorship care, the infrastructure must be developed to require GOC discussions and documentation at specified intervals along the survivorship care continuum.

5.0   DISSERTATION MANUSCRIPT 2: SURVEY

5.1   ABSTRACT

Background: Metastatic breast cancer remains a progressive, life-limiting disease. Demographic, social, patient health, and clinical factors will influence prognosis, overall length of survival, and care experienced at the EOL. The complete trajectory of care experienced at the EOL can only be known after the patient is deceased, the DPR is vital to serve as proxy in understanding this experience. Therefore, the purpose of this study is to examine the DPR's perspective on the patient's quality of EOL care and the death experience through the administration of the QODD Survey. This will allow a surrogate evaluation of the EOL experience for women diagnosed with and deceased from MBC.

Methods: This study is the first of two components of a sequential quantitative-qualitative mixed methods study design. The DPR was recruited from the following settings which included, 1) a southwestern Pennsylvania cancer clinic, 2) a regional cancer support group, and 3) two social media group platforms. Access to the QODD survey was provided.

Results: A majority of the DPR participants were male (72%, n=18), the spouse of the deceased MBC patient (64%, n=16), White (98%, n=23), and had an average of 59.84 years of age. Total survey scores ranged from 13-216, having a total possible amount of 240. The average of scores was 137.28.

Conclusion: While this sample is twenty-five DPR participants, it demonstrates the wide variability in experiences despite current national and healthcare system EOL care standards. Consideration of the individual patient wishes and how adherence to those wishes promote a high-quality EOL care experience will need to further examined in future studies.

Keywords: Quality of death and dying, metastatic breast cancer, end-of-life care

5.2 INTRODUCTION

While great strides are being made to improve the overall survival of women diagnosed with metastatic breast cancer (MBC), it still remains a non-curative, life ending illness with an average overall survival of 24-52 months after diagnosis (Laohavinij et al., 2017; Mariotto et al., 2017b; Miller et al., 2016; Santa-Maria & Gradishar, 2015). While prognosis can vary based on demographic, social, patient health, and clinical factors, goals of care discussion regarding optimal EOL care should be integrated into metastatic cancer care. The current treatment paradigm in metastatic cancer has shifted from palliative care only to include sequential, often specifically targeted therapies with the goal of not only palliation, but of improving survival, which can involve costly and toxic therapies, even as patients approach the EOL. It is vital to evaluate the current MBC patient's EOL experience with this evolving paradigm of EOL care. However, because the full experience of EOL care is only known after the MBC patient is deceased, this evaluation should be done through their previously chosen designated personal representative (DPR). Throughout the disease and treatment course, the DPR is often the person who is most closely connected to the patient serving as their support, confidant, and co-healthcare decision maker (Bernacki & Block, 2014; Dionne-Odom et al., 2019; Van Eechoud et al., 2014). However, it should be noted that due to the wide age range and varying demographics of those diagnosed with MBC, the DPR can include those who are a caregiver, next of kin, spouse, extended family member, sibling, parent, child, or friend.

Model/Framework

The QODD conceptual framework and the Cancer Family Caregiving Experience conceptual model were chosen to provide understanding and support for the research study. (Fletcher et al., 2012; Patrick et al., 2001). The main tenants of the QODD framework consist of

six domains: 1) symptoms and personal care; 2) preparation for death; 3) moment of death; 4) family (i.e., spending time with family members, pets, or being alone, familial structure, etc.); 5) treatment preferences; and 6) whole person concerns (Patrick et al., 2001). These domains can be applied to both the preferences prior to death and the perspective of the quality of dying and death after the death has occurred. The QODD survey instrument used for this study was created from these domains.

Additionally, the Cancer Family Caregiver model, was used to understand family caregivers of cancer patients related to cancer-specific stressors (Weitzner et al., 2000). As the diagnosis of cancer can affect any dynamic within the family, such as identity, roles, and daily functioning, it was important to understand the potential response and burden throughout the EOL care and treatment. These burdens can include financial needs, lack of coping strategies and self-care behaviors, minimal support directed toward caregiver health and wellbeing, stress processes, contextual factors, and the unique cancer trajectory as it relates to the caregiver (Fletcher et al., 2012). Therefore, the purpose of this study is to examine the DPR's perspective on the patient's quality of EOL care and the death experience through the administration of the QODD Survey. This will allow a surrogate evaluation of the EOL experience for women diagnosed with and deceased from MBC.

5.3   METHODS

Study Design, Sample and Setting

This study is the first of two components of a sequential quantitative-qualitative mixed methods study design. The primary setting was at a southwestern Pennsylvania cancer clinic,

which serves as a multidisciplinary center dedicated to both the research of and treatment for MBC. The DPR cohort from this primary setting was collected using the database for deceased MBC. The deceased MBC patient's name, birthdate, and date of death was received from the clinic. Using those data, the contact information (i.e., name, address, and email) of the DPR was retrieved from the EHR. A letter was then sent requesting the decedent's personal representative to participate in the study through a Qualtrics-provided link for the QODD survey.

The survey was also made available to a regional cancer support group for DPRs, and two social media group platforms who focus specifically within the MBC population. For the regional cancer support group, Cancer Caring Center, and social medial group platforms, Young Survivor Coalition and Metavivor, the snowball sampling method was utilized. Ultimately, it is unknown how many participants were contacted through these methodologies. While the Cancer Caring Center is a general cancer care support group, the PI provided the leader of the support group inclusion and exclusion criteria. If a cancer care support group participant met the eligibility criteria, a letter was given to the participant for self-selection and instructions for accessing the Qualtrics-provided link for the QODD survey. For both of the social media groups, inclusion and exclusion criteria were provided via a social media announcement for the participant to self-select their eligibility with attached instructions for accessing the Qualtrics link to the QODD survey.

Finally, in each of these recruitment groups, there was also the option for the participant to complete the survey over the phone or on paper due to physical limitations. If completed in either of these ways, consent was obtained verbally prior to completion.

Eligibility Criteria and Recruitment

Inclusion criteria into the study sample included 1) "next of kin" or "designated personal

representative" as specified from the EHR for the southwestern Pennsylvania cancer clinic for women deceased from MBC between November 1, 2016, and October 31, 2020, 2) age>18 years; 3) for the cancer support groups and social media platforms, a self-reported DPR (whether a partner, spouse, family, or support person) for a woman diagnosed with and deceased from MBC. There were no restrictions based on race, although participants needed to be able to complete the survey in English. The exclusion criteria were 1) any DPRs age<18 years of age, and 2) any DPRs for male MBC patients as this study is focusing on the female patient experience.

QODD Instrument

The quality of EOL care and the death experience was determined from the perspective of the DPR through the QODD survey. This survey is a validated and reliable 25-item tool which evaluates six different domains regarding preferences prior to death and the perspective of the quality of dying and death after the death has occurred include, 1) symptoms and personal care, 2) preparation for death, 3) moment of death, 4) family, 5) treatment preferences, and 6) whole person concerns (Downey et al., 2010a). Each of the survey questions targeted one of these six domains and assessed both the 1) frequency of an experience or event, and 2) quality of that experience or event. The frequency of these experiences were rated based on specifically provided responses. The quality of these experiences will use an 11-point Likert scale rating from 0 (terrible) to 10 (almost perfect). If any participants selected "I don't know" as their response, they were prompted to continue to the next question. The final 14 questions assessed the participant's demographic and social background as well as relationship to the deceased MBC patient.

Data Source/Data Collection

Approval was received from the University of Pittsburgh Institutional Review Board (IRB). All data collection and entry was performed by the PI. The survey data from the Qualtrics platform was extracted with verification and accuracy assessments of the data. Any disease or treatment information of the deceased MBC patient was not collected prior to the DPRs participation in the survey. Upon completion of the survey whether electronically or with the PI, all of the DPRs were able to voluntarily give or withhold their consent for participation in a future semi-structured telephone interview. To reduce any chance of repeated survey or telephone interviews, unique data similarities were reviewed.

Statistical Analysis

Descriptive statistics, including mean, standard deviation, range, and percentages, were used to summarize the MBC cohort sociodemographic characteristics, clinical factors, and QODD survey scores. The sample size was driven primarily by the determination of thematic saturation.

5.4   RESULTS

For those DPR participants recruited from the Southwestern Pennsylvania cancer clinic, there were 217 eligible persons. Of those, 188 potentially received the letter with instructions while 29 participants were excluded from the final analysis. These 29 participants were not included due to pertinent missing contact information for the DPR (n=4), any male MBC patients

(n=3), returned letters (n=21), and lack of desire to participate in future research studies (n=1).

Table 13 demonstrates the sociodemographic and clinical factors of women deceased from MBC

and their DPR for those who did choose to participate (N=25).

Table 13: Sociodemographic and Clinical of Women deceased from Metastatic Breast Cancer and their Designated Personal Representative (N=25)

Sociodemographic and Clinical Factors	MBC Cohort (n=25)
DPR Age (years)	25-95 years (*SD 14.51*), mean of 59.84 years
Patient Gender	100% Female (n=25)
DPR Gender	28% Female (n=7) 72% Male (n=18)
Hospital length (days) at the end-of-life	0-25 days (54.2%; n=13)
ICU length (days) at the end-of-life	1-7 days (16.7%; n=4)
Ethnicity	4% European (n=1) 4% Indian (n=1) 72% White (n=18) 20% Did not answer (n=5)
Race	92% White (n=23) 4% Asian (n=1) 4% Did not answer (n=1)
Education	4% High school (n=1) 16% Some college (n=4) 36% College (n=9) 44% Graduate (n=11)
Relation	4% Friend (n=1) 64% Spouse (n=16) 12% Child (n=3) 4% Sibling (n=1) 4% Parent (n=1) 4% Grandchild (n=1) 4% Caregiver (n=1) 4% Sister-in-Law (n=1)
Lived with (DPR)	32% No (n=8) 68% Yes (n=17)
Length of Relationship (years)	7-63 years (*SD14.38*), mean of 32.94 years

Table 14 shows the results of the QODD survey responses (N=25). Responses for questions 1 through 10 were scored on a 6-point Likert scale (none of the time, a little bit of the time, some of the time, a good bit of the time, most of the time, all of the time, and don't know). For each of those questions, participants were also asked to rate the experience on a 0-10 scale (ranging terrible [0] to almost perfect [10]). These experience scores were then categorized into three categories: poor (score 0-4), good (score 5-7), and excellent (score 8-10). Survey responses for questions 11 through 21 were scored on a 3-point Likert scale (yes, no, and don't know). For each of these questions, participants were also asked to rate the experience on a 0-10 scale (ranging terrible [0] to almost perfect [10]). These experience scores were also categorized as: poor (score 0-4), good (score 5-7), and excellent (score 8-10). Total survey scores ranged from 13-216, having a total possible amount of 240. The average of scores was 137.28.

Table 14: QODD survey responses (N=25)

Frequency Question	Responses							Experience Question	Experience Score (0-10)			
	None of the time	A little bit of the time	Some of the time	A good bit of the time	Most of the time	All the time	Don't know		0-4	5-7	8-10	N/A
How often did your loved one appear to have his/her pain under control?	4% (n=1)	28% (n=7)	12% (n=3)	12% (n=3)	24% (n=6)	16% (n=4)	4% (n=1)	How would you rate this aspect of your loved one's dying experience?	32% (n=8)	32% (n=8)	32% (n=8)	4% (n=1)
How often did your loved one appear to have control over what was going on around him/her?	8% (n=2)	32% (n=8)	36% (n=9)	12% (n=3)	8% (n=2)	4% (n=1)	-	How would you rate this aspect of your loved one's dying experience?	56% (n=14)	28% (n=7)	16% (n=4)	-
How often was your loved one able to feed her/himself?	32% (n=8)	12% (n=3)	12% (n=3)	4% (n=1)	16% (n=4)	16% (n=4)	8% (n=2)	How would you rate this aspect of your loved one's dying experience?	44% (n=11)	24% (n=6)	24% (n=6)	8% (n=2)
How often did your loved one appear to breathe comfortably?	20% (n=5)	12% (n=3)	24% (n=6)	16% (n=4)	20% (n=5)	8% (n=2)	-	How would you rate this aspect of your loved one's dying experience?	48% (n=12)	28% (n=7)	24% (n=6)	-
How often did your loved one appear to feel 6aat peace with dying?	20% (n=5)	4% (n=1)	20% (n=5)	12% (n=3)	16% (n=4)	4% (n=1)	12% (n=3)	How would you rate this aspect of your loved one's dying experience?	32% (n=8)	40% (n=10)	20% (n=5)	8% (n=2)
How often did your loved one appear to be unafraid of dying?	8% (n=2)	12% (n=3)	16% (n=4)	8% (n=2)	28% (n=7)	12% (n=3)	16% (n=4)	How would you rate this aspect of your loved one's dying experience?	36% (n=9)	28% (n=7)	20% (n=5)	16% (n=4)
How often did your loved one laugh and smile?	48% (n=12)	12% (n=3)	16% (n=4)	8% (n=2)	8% (n=2)	4% (n=1)	4% (n=1)	How would you rate this aspect of your loved one's dying experience?	62.5% (n=15)	32% (n=8)	4.2% (n=8)	-
How often did your loved one appear to keep his/her dignity and self-respect?	8% (n=2)	16% (n=4)	4% (n=1)	20% (n=5)	20% (n=5)	28% (n=7)	4% (n=1)	How would you rate this aspect of your loved one's dying experience?	36% (n=9)	40% (n=10)	24% (n=6)	-
How often did your loved one spend time with his/her family or friends?	8% (n=2)	12% (n=3)	8% (n=2)	12% (n=3)	16% (n=4)	44% (n=11)	-	How would you rate this aspect of your loved one's dying experience?	20% (n=5)	20% (n=5)	60% (n=15)	-
How often did your loved one spend time alone?	28% (n=7)	40% (n=10)	8% (n=2)	8% (n=2)	12% (n=3)	-	4% (n=1)	How would you rate this aspect of your loved one's dying experience?	28% (n=7)	16% (n=4)	56% (n=14)	-

Table 15: QODD Survey Responses (N=25)

Frequency Question	Responses			Experience Question	Experience Score (0-10)			
	Yes	No	Don't Know		0-4	5-7	8-10	N/A
Was your loved one touched or hugged by his/her loved ones?	92% (n=23)	4% (n=1)	4% (n=1)	How would you rate this aspect of your loved one's dying experience?	12% (n=3)	12% (n=3)	72% (n=18)	4% (n=1)
Were all of your loved one's health care costs taken care of?	76% (n=19)	16% (n=4)	8% (n=2)	How would you rate this aspect of your loved one's dying experience?	12% (n=3)	28% (n=7)	56% (n=14)	4% (n=1)
Did your loved one say goodbye to loved ones?	40% (n=10)	52% (n=13)	8% (n=2)	How would you rate this aspect of your loved one's dying experience?	52% (n=13)	16% (n=4)	28% (n=7)	4% (n=1)
Did your loved one clear up any bad feelings with others?	20% (n=5)	52% (n=13)	28% (n=7)	How would you rate this aspect of your loved one's dying experience?	16% (n=4)	40% (n=10)	12% (n=3)	32% (n=8)
Did your loved one have one or more visits from a religious or spiritual advisor?	48% (n=12)	52% (n=13)	-	How would you rate this aspect of your loved one's dying experience?	16% (n=4)	20% (n=5)	52% (n=13)	12% (n=3)
Did your loved one have a spiritual service or ceremony before his/her death?	28% (n=7)	72% (n=18)	-	How would you rate this aspect of your loved one's dying experience?	16% (n=4)	20% (n=5)	48% (n=12)	16% (n=4)
Did your loved one receive a mechanical ventilator (respirator) to breathe for him/her?	4% (n=1)	96% (n=24)	-	How would you rate this aspect of your loved one's dying experience?	8% (n=2)	28% (n=7)	52% (n=13)	12% (n=3)
Did your loved one receive dialysis for his/her kidneys?	4% (n=1)	96% (n=24)	-	How would you rate this aspect of your loved one's dying experience?	4% (n=1)	20% (n=5)	56% (n=14)	20% (n=5)
Did your loved one have his or her funeral arrangements in order prior to death?	44% (n=11)	56% (n=14)	-	How would you rate this aspect of your loved one's dying experience?	24% (n=6)	28% (n=7)	40% (n=10)	8% (n=2)
Did your loved one discuss his or her wishes for end of life care with his/her doctor -- for example, resuscitation or intensive care?	68% (n=17)	24% (n=6)	8% (n=2)	How would you rate this aspect of your loved one's dying experience?	16% (n=4)	33.3% (n=8)	48% (n=12)	4% (n=1)
Was anyone present at the moment of your loved one's death?	92% (n=23)	4% (n=1)	4% (n=1)	How would you rate this aspect of your loved one's dying experience?	20% (n=5)	28% (n=7)	48% (n=12)	4% (n=1)

Question 22 is scored based on four possible responses: awake, asleep, in a coma or unconscious, and don't know. This experience was rated on a scale of 0-10, with 0 being "terrible" and a score of 10 as "almost perfect."

Table 16: QODD Survey Responses (N=25)

Questions	Responses				Experience Question	Experience Score (1-10)			
	Awake	Asleep	Coma or Unconscious	Don't Know		0-4	5-7	8-10	N/A
In the moment before your loved one's death, was he/she:	4% (n=1)	32% (n=8)	52% (n=13)	12% (n=3)	How would you rate this aspect of your loved one's dying experience?	16% (n=4)	32% (n=8)	40% (n=10)	12% (n=3)

Finally, question 23-25 was scored based solely on an experience question scale of 0-10 (ranging from terrible [0] to almost perfect [0]).

Table 17: QODD Survey Responses (N=25)

Question	Experience Score (1-10)		
	0-4	**5-7**	**8-10**
Overall, how would you rate the quality of your loved one's dying?	40% (n=10)	32% (n=8)	28% (n=7)
Rate the care your loved one received from all doctors and other health care providers (including nurses, caseworkers, and other health care professionals) during the last several days of his or her life.	24% (n=6)	16% (n=4)	60% (n=15)
Rate the care your loved one received from his or her doctor during the last several days of his or her life.	40% (n=10)	12% (n=3)	48% (n=12)

5.5   DISCUSSION

After its initial conception, the QODD survey has been widely evaluated for both its psychometric properties (Hales et al., 2010; Kupeli et al., 2018; Lendon et al., 2015; van Soest-Poortvliet et al., 2013; Van Soest-Poortvliet et al., 2011; Zimmerman et al., 2015) and validation in other international populations (Gerritsen et al., 2017; Heckel, Bussmann, Stiel, Ostgathe, et al., 2015; Heckel, Bussmann, Stiel, Weber, et al., 2015; Pérez-Cruz et al., 2017). Additionally, this extensively used tool has also been appraised for use in a wide range of patient populations, locations of dying, and terminal disease types (Curtis et al., 2012; C. R. Levy et al., 2005; Sellers et al., 2015). While there are still several areas of improvement and confirmation studies to be conducted in future populations and healthcare settings, it has proven to be helpful in a number of different contexts (Curtis et al., 2013).

Although there have been studies associated with a specific disease type (i.e., interstitial lung disease) and a wide array of advanced cancers (i.e., gastrointestinal cancer, lung cancer, gynecological, genitourinary, solid cancer, hematologic malignancies, etc.), as far as this author is aware, there has not been a specific study which focuses solely within the MBC population (Braun et al., 2014; Choi et al., 2019; Downey et al., 2010b; Hales et al., 2014; Koyauchi et al.,

2021; Mah et al., 2018, 2019). Additionally, some studies have used different versions of the QODD survey depending on the target audience. This has made a direct comparison between this MBC-focused group and other studies challenging.

Most notably, in this surveyed participant group, 40% indicated that their overall experience of the dying process alongside their loved one was an experience score between 0-4, indicating it was a poorly experienced event. Yet, 60% indicated that the overall care received by the healthcare team was an excellent experience, rated between 8-10. While the responses varied with each of the questions, two questions were in the majority as considered poor experiences. First, when the DPR was asked to rate "how often their loved one appeared to have control of the situation," they rated the experience as poor with a score between 0-4 (n=14; 56%). Second, the response to the question, "how often did your love one laugh or smile," 62.5% (n=15) rated this as a poor experience. While it is important to note the pattern of how the DPR rated the frequency and experience of an event at the EOL, it was also important to understand how those survey scores were or were not in congruence with a patient's wishes and why the DPR attributed those scores to their loved ones' experience. For example, for some women with MBC, it is very important to have a religious or spiritual advisor present at the EOL. However, if they did not have a spiritual advisor present but wished to, this remains a component of a poor-quality experience at the EOL. For other women with MBC, this is not important and in fact, would be a hindrance to their well-being at the EOL. Ultimately, the presence of a spiritual advisor is welcomed only if in accordance with their wishes. Therefore, it is vital to consider the individual patient wishes and how adherence to those wishes will promote a high-quality EOL care experience for all those involved.

5.6   CONCLUSION

5.6.1   Strengths and Limitations

There are several strengths to this study. The range of DPR demographic and social data demonstrates variability in the potentially unique and varying challenges for both the patient and DPR at the EOL. Additionally, while primarily centered around one facility, this DPR cohort is collected from five different states which gives variation to EOL care experiences. We acknowledge that with the smaller sample size, the distribution of frequency and experience survey scores could be different than what is currently presented for this study. Therefore, for the next component of the study in order to ensure full understanding of the MBC experience for women at the EOL, it is vital to assess more deeply the DPR's perspective of the patient experience at the EOL through a qualitative interview.

6.0   DISSERTATION MANUSCRIPT 3: INTERVIEW

6.1   ABSTRACT

Background: Metastatic breast cancer is a challenging diagnosis and carries significant disease and treatment burdens that must be tailored to the individual patient living with this disease. While some of these burdens are being currently recognized and supported, this unique patient population requires reexamination into what promotes high quality EOL care. This reexamination will allow for healthcare providers to target their care interventions towards current MBC patients in a meaningful and streamlined approach. Therefore, the aim of this study was to explore the DPRs own, and their perception of the patient's view of EOL care and death quality through a qualitative semi-structured telephone interview.

Methods: Semi-structured telephone interviews were conducted with the DPR of patients, diagnosed with, and deceased from metastatic breast cancer. All interviews with recorded and transcribed by the primary investigator. Constant comparative analysis was utilized to uncover themes and categories.

Results: There were sixteen interviews conducted. Primary categories that emerged describing high quality care at the end-of-life were sources of resilience, communication experiences, supportive systems, and knowledge regarding both disease, treatment, and bereavement care. There was minimal frustration or regret around experiencing traditional poor-

quality end-of-life care indicators (i.e., acute care utilization, aggressive chemotherapy, and minimal hospice care). Additionally. there was a verbalized need for EOL care discussions, regardless of difficulty, as many acknowledged they would have felt more prepared.

Conclusion: Our results reinforce and expand important areas for healthcare providers to target in providing high quality EOL care. Continued research is necessary to confirm the findings and direct interventions that can be individualized according to the dynamic DPR and patient care needs.

Keywords: End-of-life care, poor quality end-of-life care indicators, qualitative research, metastatic breast cancer, resilience, communication, support, and knowledge

6.2   INTRODUCTION

Metastatic breast cancer (MBC) is a progressive, non-curative disease, with multiple treatment options that allows health care providers to offer sequential treatments in attempts to prolong life (El Saghir et al., 2011; Otte et al., 2017; Santa-Maria & Gradishar, 2015). Overall prognosis and prescribed treatments are based upon several clinical factors, including tumor subtypes. (Alečković et al., 2019; El Saghir et al., 2011; Miller et al., 2016). In fact, treatment algorithms, such as those from the National Comprehensive Cancer Network (NCCN), are derived based on tumor subtype and can include hormonal therapy, chemotherapy, targeted therapy, immunotherapy, and radiation therapy (Etan et al., 2020; Gradishar et al., 2015).

Because toxicities and side effects from these therapies, as well as the signs and symptoms of advancing cancer, can cause patient related distress, it is vital that the patient experience, throughout treatment and particularly at the EOL, is in concordance with their wishes and goals of care. (Borreani et al., 2012; Clayton, Butow, Arnold, et al., 2005; El-Jawahri et al., 2017, 2020; Haque et al., 2020; Sarfati et al., 2016; Steinhauser et al., 2000; Torre et al., 2017). However, the long list of treatment options can delay the provider's discussion of prognosis, disease trajectory, and preparation for EOL care (van der Velden et al., 2020). Additionally, the patient or DPR may wish for only positive or hopeful information, however, this too can also dynamically change through the treatment and disease course (Bergqvist & Strang, 2019; Collins et al., 2017; Schofield et al., 2006). Therefore, the challenge for healthcare providers is often balancing the provision of care and maintenance of hope with the need to honestly communicate severity of the disease and prognosis for achieving high quality, goal concordance care (Ginter, 2020; Ray et al., 2006). Therefore, the aim of this study was to explore the DPRs own, and their perception of the patient's view of EOL care and death experience

through a qualitative semi-structured telephone interview. This allows for a better understanding of how current EOL quality standards, today's care expectations, and patient goals of care and wishes are intersecting.

6.3   METHODS

Study Design, Sample, and Setting

This study is reporting on the qualitative component of a sequential quantitative-qualitative mixed methods approach, examining the quality of EOL care received for women diagnosed with MBC according to the perspective of their DPR. Interviews were conducted over the phone and recorded with the PI. The study's protocol was approved by the University of Pittsburgh IRB.

DPR participants were recruited from four different groups: 1) a southwestern Pennsylvania designated cancer center outpatient clinic for MBC patients who were deceased from November 2016 to October 2020, 2) a local Pittsburgh cancer support group for DPRs, and 3) two social media group platforms with an MBC emphasis. For the cancer support group and social media group platforms, DPRs were eligible for participation if they were 18 years of age or older or were a self-reported DPR (whether a partner, spouse, child, parents, family, or friend) of a woman who passed away from MBC.

Data Source/Data Collection

Regardless of recruitment locations, the DPR participants were provided a Qualtrics-specific link to either read the consent form and agree to participate in the QODD survey online,

take the survey, or decline to participate. They also had the opportunity to call the provided research team number to take the survey with assistance over the phone from the PI or have a paper copy sent to their home address. Permission was granted to be recontacted for the qualitative interview by the PI if the DPR gave their email, phone number, or availability at the end of the QODD survey.

At the scheduled or designated available time for the telephone interview, the PI consented each DPR over the phone and verbal consent was received before the interview began. If the DPR chose to complete the QODD survey over the phone with the PI or with a paper copy, the qualitative interview consent form was still reviewed and verbal consent obtained before proceeding.

Prior to the telephone interviews, an interview guide was developed according to a literature review and expert opinion regarding the MBC population care needs and trajectory of disease, advanced cancer care concerns, and components of high quality and poor quality EOL care. During the interview, DPR's were asked to give their perception regarding topics, such as 1) the experiences surrounding care, 2) support, 3) effects on daily activities, planning, and priorities, 4) end-of-life, and 5) aftercare or bereavement. As needed, the PI used additional prompts to promote more detail to responses, additional information, or for clarification. After the interview was conducted, the PI made notes regarding the general impressions from the interview.

Sample Size Justification

Constant comparative analysis for semi-structured interviews were conducted. While there is no definitive sample size requirements, it is suggested that a sample size between 10-20

persons can provide a meaningful capture of content and data saturation, that is, no new information is being uncovered (Creswell, John W. 1998; Malterud et al., 2016; Turner-Bowker et al., 2018; Vasileiou et al., 2018).

Analysis

Interviews were audio recorded and transcribed by the PI. Additionally, after each semi-structured interview was completed, their QODD survey responses were linked. After preliminary interviews were conducted (n=5), an initial codebook was developed regarding the DPR's perceptions. After the fifteenth interview was conducted and to establish reliability, two researchers (R.B. and K.A.) coded the transcripts independently for interview five and interview ten. They met to discuss coding of the manuscripts. Using constant comparative techniques, the coders compared previously designated codes and current transcripts for categories and emerging themes. Consensus was reached and ensured inter-rater agreement, with revisions done as needed. Ultimately, primary coding for ten percent of the DPR cohort was conducted by two coders independently.

After all the interviews were completed (n=16), the PI used a combination of manual and NVivo12 software (version 12), to code content from the interviews by the PI, an expert clinical nurse. As additional interviews were conducted, additional codes were added. While the text was examined for keywords and terms (i.e., GOC, EOL care, poor death, etc.), it was not be the sole criteria used for collapsing or eliminating data. Moreover, it was considered valuable if these topics were not found in the interview transcript as it may carry a meaningful discovery. The finalized codebook included definitions, sub-codes, and themes.

6.4   RESULTS

Of the 25 individuals who participated in the QODD survey, every individual indicated their willingness to be recontacted for the qualitative interview. However, after all individuals were recontacted at least twice, 16 individuals (64%) actually participated in the interview. Our DPR sample had a male majority (81.25%), were older than 60 years of age (62.5%, n=10), and had the relationship of "spouse" for the women diagnosed with MBC (81.25%, n=13). Table 18 displays this group's demographics and characteristics.

Table 18: DPR and MBC patient demographics and characteristics (N=16)

DPR and MBC Patient Demographics and Characteristics	
Demographic Factors and Characteristics	**Range, standard deviation, and/or average Or % (n)**
DPR Age (years)	25-95 years of age *(SD 15.99)*, 62.25 mean of years
DPR Gender	
Female	18.75% (n=3)
Male	81.25% (n=13)
Patient Gender	
Female	100% (n=16)
Hospital length (days) at the end-of-life[1]	1-25 days, 11.5 day mean
ICU length (days) at the end-of-life[2]	1-7 days, 4 day mean
Ethnicity	
European	6.25% (n=1)
White	81.25% (n=13)
Not disclosed	12.5% (n=2)
Race	
White	93.75% (n=15)
Not disclosed	6.25% (n=1)
Education	
High School	6.25% (n=1)
Some College	6.25% (n=1)
College	43.75% (n=7)
Graduate or Professional School	43.75% (n=7)
Relation	
Friend	6.25% (n=1)
Spouse	81.25% (n=13)
Child	6.25% (n=1)
Extended Family	6.25% (n=1)
Lived with	
No	12.5% (n=2)
Yes	87.5% (n=14)
Length of Relationship	7-47 range of years *(SD 12.85)*, 31.17 mean of years

1: Not applicable to all MBC patient experience; (n=10)
2: Not applicable to all MBC patient experiences; (n=2)

Throughout the interview, each participant was asked to recall whether or not their loved one experienced any of the poor quality EOL care indicators (Earle et al., 2003, 2004, 2005). The results are displayed in Table 19.

Table 19: Poor quality End-of-Life Care Indicator Occurrence (N=16)

EOL Care Indicators	MBC Cohort % (n)
New chemotherapy 30 days prior to death	
No	56.25% (n=9)
Yes	37.5% (n=6)
Unknown	6.25% (n=1)
Any chemotherapy 14 days prior to death	
No	93.75% (n=15)
Yes	6.25% (n=1)
One or more ER visit in the last 30 days	
No	50% (n=8)
Yes	43.75% (n=7)
Unknown	6.25% (n=1)
One or more hospital admission in the last 30 days	
No	56.25% (n=9)
Yes	37.5% (n=6)
Unknown	6.25% (n=1)
ICU admission in the last 30 days	
No	87.5% (n=14)
Yes	6.25% (n=1)
Unknown	6.25% (n=1)
Hospice 3 days or less before death	
No	68.75% (n=11)
Yes	31.25% (n=5)
Death in the acute care setting	
No	68.75% (n=11)
Yes	31.25% (n=5)

Of those who were able to completely recall the presence or absence of poor quality EOL care indicators (n=15), 26.7% (n=4) reported that their loved one did not experience any poor quality EOL care indicators. For those MBC patients who did experience at least one poor quality EOL care indicator (n=11), the reported range per patient was between 1-4. For 36.4% of those patients (n=4), the experience of these indicators often clustered in combinations around

acute care utilization (i.e., more than one ER visit in the last 30 days, more than one hospital admission in the last 30 days, and death occurring in the acute care setting). It should also be noted that while four patients did not meet the criteria of experiencing hospice care three days or less before death, four MBC patients started hospice between 4 days-2 weeks prior to death.

Four major categories emerged from the interview data: resilience, communication, support, and knowledge. Each one of these categories, regardless of the presence or absence of poor quality EOL care indicators, played an important role in the perception of the DPR regarding the quality of death experienced by their loved one.

Resilience

Many of the DPR participants alluded to the idea of resilience, particularly in the area of transitions or adaptations made, that was vital to their experience. Together, these two themes seemed to aid the DPR and their loved one in acclimating and processing through the MBC diagnosis and treatment, particularly during EOL care. Table 20 displays a sample of the participant's discussion centered around this topic.

Table 20: Examples of Resilience from DPR Participants

Examples of Resilience from DPR Participants		
Themes	Categories	Exemplars
Transitions	Closure	"…and then everybody came here that last weekend-the weekend before the weekend she died. Umm, we had, we had 30 people here - so we had, we had great closure. The whole family was here. Everyone came from all over. Umm, and, and it was kind of exhausting for her, but she wanted to do that…" (1)
	Care	"I mean, the hope would have been that we could have figured out… that we could stabilize her long enough to get her on another kind of medicine but that was… things went so rapidly, and she just didn't respond to any of the medicines anymore that they were able to give her at, umm, [second hospital] before we could get back into Dr. [oncologist]'s office." (2)
	Roles	"Now she also processed, uhh, her, uhh, let's say her journey with cancer through writing also. I mean, I told you she was a health writer, writer/editor, and she also published a blog for several years regarding her cancer journey. And she, umm, yea, and she published it all online and she shared a lot about what it took – or what the impact was of being a patient and person suffering with this. And in addition, she was an advocate for, umm, cancer treatment, cancer funding and for, umm,

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		early screening and stuff like that. So, she was trying to be a health educator and communicator throughout her entire journey based on her experience and things that she could, that she could get the word out for too. So, she wasn't just, she wasn't just a patient, she was also trying to be an advocate for, uhh, what it means to have breast cancer and be a patient and stuff like that." (2)
		"I mean, I got to the point where we didn't really need the home nurse, I was draining her. Doing it myself, every morning." (1)
		"Well, well I uhh retired early because…*(incomprehensible speech)* retired September 2018 because she…someone was going to have to be here for her. She couldn't just be here by herself – better around. So uhh, I retired so I could take care of her full time and – I mean, her mom came over, her sister came over several times." (4)
	Change in role between the DPR and PT	"I got food for her and I went to the grocery store to get the things that she asked for. You know, I learned how to wash the clothes. Umm, umm, you know, and I helped her getting to the bathroom, and, and in taking care of some problems in that regard." (24) In the past I could talk about….but I didn't unless she did first.
	Changes for DPR after death of loved one	"And then when she died, I guess I am still mad it came out the way it came out. And I don't know, if you had sat down with me, given me a four hour lecture PowerPoint, and told me everything that could and could not happen… would we still be having this conversation in this manner, two years after she died? Yeah… probably because what I'm mad about is that she died. *(chuckles)* So…" (1)
Adaptations	Emotional	"But, you know, both of them said, "there are good outcomes here." Somebody should have told some bad outcomes were too, so we understood and were more prepared." (1)
	Financial	"She was always having to be the one, the liaison and stuff, between the insurance, making sure the insurance company were billed correctly and it's just a mess, you know." (2) "Because, umm, we traveled, we vacationed, I mean, we did everything. Umm, we did as much as we could fit in. Um, basically, depleting my savings but fortunately I have pensions so, it's OK. But we knew that when we were depleted *(chuckles)*. Nonetheless, we did, we did a lot of stuff." (1)
	Physical	"Then she lost control of her bladder – she wasn't able to pee or anything so she had to use a catheter. So, ohh, for the last year, I want to say last year or a month or two months, she was in a wheelchair and umm. So, I mean we went and did a lot of things. I put her in another wheelchair and then off we go. I'd take her out of the car and put her in a wheelchair and then we would go and do whatever we wanted to do, so. But she uhh, I would say that it was not expected but I don't know umm, I don't know what could have been done different, so…" (4)
	Priorities (i.e., pain control, comfort, minimize burdens, time allotment)	"Well, we decided to try and go ahead and live our lives the best we could. And we did." (26) "No, I think she probably felt that she could get better treatment for pain there and, and her pain was substantial. If it wasn't treated, it was substantial. Umm, they could, they could comfortably manage her pain umm on the sixth floor. Whereas, if she were home, you know, she wouldn't be getting that quality of care." (24)

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Communication

A second major category was communication, specifically with whom it occurred, how it occurred, the manner in which it occurred, and the type of content. The DPR's verbalized that much of the communication quality or delivery style set the tone for their entire approach to understanding and living alongside their loved one with MBC. If done poorly, this was often the largest source of frustration during the disease progression and treatment course. At the EOL, this lack of satisfactory communication led to a feeling of unpreparedness and bereavement difficulties.

Table 21: Examples of Communication from DPR Participants

Examples of Communication from DPR Participants		
Themes	Categories	Exemplars
Content	Prognosis	"I believe he was the one that ultimately said that the scans are showing some progression. And or that, or that the blood test results were showing some heated activity and then from there, uhh, they confirmed that that was the case and they started doing – or that doctor started doing research on what, how to treat this." (2)
	Treatment/Medications	"So, he's, he's…part of the reason he was picked because he was young and he was willing to sort of you know, think outside the box a little and suggest things, umm, and - that seem to be scientific, evidence based research, you know, that tried these things or this combination might not be the normal cocktail – like, there could be success. So…but he was very honest with her about the odds, given the rarity of her type. Umm, that the odds weren't…that she was going to die early." (14)
	End-of-Life	"They explained to us, look, things are just progressing so fast that the medicine is not stopping it and this isn't going to work. So, they were upfront in that regard and then once, once that kind of decision was recognized, when that point was recognized, that [second hospital] came in with- I guess it's called a palliative care team?" (2)
	Grief	"Yea, yea. I'm an only child. My mother died and my father died and, uhh, and you know, that's hard. But uhh, this is the first time, in my life, that I experienced anything, to me, this devastating or of this nature and that was from day one until the end. Uhh, it was devastating for me and I tell people this all the time, umm, you know, I never went through anything like this. The whole world was upside down up until right now as we speak, you know. So, this is fourteen months later, uhh. Losing your parents is hard. I never went through nothing like this, you know. Sooo, uhh, this is a first for me to go through like this." (12)
	Bereavement	"No, there was plenty of follow-up, I mean it was primarily from hospice. Looking back, I think that's where it would normally come

		from. It's not that…not from Dr. [treating Oncologist] or anyone in Altoona about her, you know, treatment. It was more that, you know, anything I needed help with, hospice was more than happy to provide from bereavement to counselors or anything." (4)
	Discussion of Goals of Care (i.e., barriers, preferences about treatment, and facilitators)	"Umm, well, ever since…there's some confusion on how hospice would work and if she could…if she had to give treatment to be on hospice. So, since…we were told that she had to give up treatment to be on hospice, well then she was not going to give up treatment." (4)

"Umm, there was lots of conversations, umm, and she, she decided she wanted to will her body to science, she decided she wanted to be able to do death with dignity…umm, so these were, these were all things that…many of these things were what I signed affidavits saying she was of a sound mind when she wanted to donate her body to science. And, and so we were there with all of them and even though the kids were young, they were, they were included in the conversations to an extent as well." (14)

"It didn't really come up. I thought. I'll tell you what – we didn't talk about it – me and my wife, but the doctor's one PA, which we got kind of close to, uhh, because it turns out, that I was friends with her father, and you know, we had…Yea, it was one of these small worlds kind of - so I knew her father's family very well. They were some of my best friends growing up. Well anyway, uhh, I don't remember how long before the end, you know, maybe a month or two, and we went in for a chemo appointment and we see the PA and it was this girl. And a, and it was after my wife had a scan and that and I think, uhh, I don't remember exactly how this came out but some of the news was good and some was bad. But I do remember these words from the PA word for word. She said, "I think it's time we start looking at the big picture." (12)

"Uhh, well we didn't have extensive discussions. I guess that, uhh, was one of the *(mumbling slightly)*, and I'm not sure if you read my responses. One of the reasons I was a little bit, uhh, disappointed with regard to the EOL care. Uhh, I don't think in my mind, and again, I don't think we were prepared enough with regard to how serious the situation was when we got there. We were kept being given, "oh well, we're going to try this, we're going to try that." Clearly, we were receptive to it. And, I guess, I didn't feel like we got enough counseling with regard to well, "hey, this is a more blunt discussion as to how serious things were." (9) |
	Inappropriate/Missing	"And her cell type was misdiagnosed. And that doctor later, umm, he left and he was went to another hospital and had some legal troubles. I think, like he was a complicated guy. So, by the time we got to [treating Oncologist]'s office, it had been...it had been too long." (6)
	Abrupt	"The one thing that happened at the very end of her life. Umm, about two weeks before the end of her life, before she died, she got some test results back that were not good. And nursing staff from [treating Oncologist]'s office, you know, told her like, "ok, it's done now. You are done with treatment." "You need to call hospice." And umm, my recollection of it was that [patient] interpreted that as fairly abrupt and she did not want to believe it." (6)
	Balance	"He's (oncologist) a positive, positive influence. And, I mean, he was always uhh, he was always looking for a way to make it better. No, he was actually very upfront about everything. I mean, he was always,

Quality/Delivery		you know, "this is what's going on, this is what we're doing, this is what we're trying." And I mean, he was always, uhh, you know, he always tried to keep you abreast of everything that he was doing." (17)
	Hostile/Negative	"And it wasn't meant with no harm or no intent. And, uh, my wife never said a word. She just sat there. But the nurse would not let it go. She… "you don't touch no, no staff member. Don't you ever do that…*(garbled speech here – due to mock yelling)*" You know, and I thought that was rather cruel and harsh for a patient that was dying. Because I honestly, would not expect that from a medical care person, as a nurse, or someone to that effect." (12)
		"She wanted to try the alternative, umm, methods and, uhh, they didn't work. And he was like, "eh, it that's what you want. I won't force you, but I will be in support of you." Anyway, whenever we started, he just "boom, boom, boom," laid down the law so to speak, "here's what we're gonna to do for eight weeks or whatever, you know, twice a week." Umm, and I think my expectations are not really what's important. Her expectations was that he was going to be more, umm… more involved, you know, through the nursing staff and all that. And the nursing staff, they were wonderful, they were. Umm, but he was just…like when they, when they screwed up a couple times with the, umm, the pain meds, kind of…*(muffled words)*. And uhh, we wanted to talk with him, about maybe changes that my wife would want, and, he was nowhere to be found. And, caused the staff – the front office staff at the window that they would, uhh, you know, inform him of what she wanted and he, he just said, "well, I didn't hear that. Don't talk to them, call my office." And it really didn't, uhh, it really did not make a difference, so." (8)
	Compassionate/Kind	"Well, this radiologist….I don't know exactly what he was doing but she was, she was uhh really taken with his confidence and his ability to discuss what was going to be done and his kindness. Because I think, I think he was probably in a position where frequently dealing with people who are late in life and he was just a very, very compassionate person." (24)
	False Hope	"So, uhh. That was – whether it was from Dr. [treating Oncologist]. I don't know, she was trying to always be optimistic, but again, at some point, we need to uhh, to you know, face, face the issues." (9)
		"So, I think, it could have been just a regular appointment or just one meeting to actually discuss, "hey, this is what's on the table." Whether it's uncomfortable for everyone or not, it just needed to be a set time that never really happened. Like I said, he did visit her without me there and I would talk to him on the phone and say, "this is what we need to discuss" and then he would talk about a clinical trial in June. And I was like, "that's false hope." We don't need that. We don't need that kind of fluff. We need more reality diagnosis." (22)
	Honest/Truthful	"When all this stuff occurred, right, is that the way that this normally looks, they said, is that you'll go along, chugging along, like relative normalcy, taking medicines and maybe having some, some symptoms and side effects of the medicines and things like that and, but, but the general, the way you feel – you'll probably chug along for a long, long time - for some extended period of time. And they said, they said but when it changes, it will change dramatically. And so, it will be like you're going along on a hill or a plateau and then it will go off of a cliff… and that's what it will look like." (2)
	Apathetic	"Uhh, the PA – even when we seen both of them – the PA would come

		in first. The PA would review the results of my wife's latest scan and go over everything and, you know, spend time with you. And then, if it was a time that we were going to see the doctor also, when she left, she would say, "the doctor will be in shortly." And he would come in, and, there were times like, to be honest with you, I was a little upset, because it was like, "boom, boom, boom." In and out. This is what we're gonna do, if that's ok with you, we're gonna try this or you know, "I'm not giving up yet, ok, alright, nice see you next time." Gone. So, umm, yea, so, you know, basically that's how it was with the doctor." (12)
	Absent/Lacking	"Never heard from anybody again. Never heard from anybody again, uhh, and I personally sent a card to that office, thinking certain people there, you know, the one nurse, uhh, that admitted the chemo at times, not every time. She was, umm, and not…and this isn't going to happen all the time…but another small world thing. That nurse, she went to the same high school as my wife and she was a couple years older than my wife but was in…but went to school with my wife's older sister. They were the same age as the nurse. So, you had that, down home feeling there at [first hospital], the breast clinic, you know. You had connections there. And, all that, like you went out to the pasture and died at another facility and all contact was lost. If something…yea, they could have reached out a little bit or Dr. [treating Oncologist] himself or you know. Yea, I do think they could have reached out. For all the years my wife had been treated, remember, she had been…she went through this with two battles for seventeen years." (12)
	Miscommunication	"I, I asked... so yeah. So, I asked...the reason I bring it up is because I specifically said, you know, what are survival rates for this? And both the nurse and, and, and I don't… I'm not accusing anyone of anything, I don't want mistake this cause it's an emotional issue and I sound more emotional then it probably needs to be but… but, you know, both of them said, "there are good outcomes here." Somebody should have told some bad outcomes were too, so we understood and were more prepared. Now, that doesn't mean that we didn't have responsibility - that we didn't read on our own and we understand the seriousness of it, but I'll give you an example of where, again, people were saying, in my opinion,…people let us down a primrose path." (1)
	Genuine/Supportive	"Umm, to to go back that far, is really hard to remember but in the beginning I know she definitely felt that she was getting what she needed. Umm, she had multiple occurrences and multiple times of remission. So, in the beginning, I think she felt comfortable – *(chuckles)* in the first decade – if that makes any sense." (22)
Timing	Proactive	"But my brother was there for most of it and at, one point, after about two years they did…she made an appointment and had an additional visit with palliative care, umm, to just sort of talk about what they needed, to think about that they hadn't so far." (14) "And uh, so he sends me an email back right away. I mean the guy was phenomenal for communicating. Umm, and he says, "[DPR], she is very sick. You shouldn't delay his [deployed son] return." *(tearful voice)* And so in that moment, at that moment, I understood for the first time somebody in authority- a medical person-was telling me, "we're at the end," right. And that's the first time I actually understood it or heard it." (1) "So [patient] and I had wills, she had a living will. It never really came to that. Umm, the, so, we certainly discussed, you know, what, what

		would be her desires, you know, when she can't make decisions for herself anymore. Umm, and so I already knew- we were already on the same page as far as what, what that would look like, right." (2)
	Delayed	"Anyway, it's just, it is psychologically, uhh, stressful to, to uhh, not know what's going on and to have doctors say, "you know, I need to get in touch with the other doctor." But I would say, the, the whole back and forth process took that, I mean, uhh, I mean, the back and forth part never went away. Because Dr. [oncologist] was never at [second hospital]. We were always working with another doctor who happened to be in front of us at the time. But, umm, but it's not like it took four days to get in touch with them. It took probably, I don't know, like I can't remember off the top of my head, but it took at least a day – two days, something like that – you know, when your loved one is in pain and, and the scans are saying things are progressing and you know that the only thing to stop them from progressing is some type of medicine and nobody can make a decision on what type of medicine that should be or what the next step is… that's stressful." (2)

Support

The perception of support and, if felt, the absence of support was a huge component of care and need for both the DPR and the MBC patient. Whether received from the healthcare team, family (i.e., immediate or extended), spiritual advisors, or monetarily, these areas played a dynamic role with how well care was adapted to during treatment, at the EOL, as well as how well the DPR adapted to life after their loved one passed away. This was particularly felt when the DPR discussed the transition between seeking active treatment options in the clinical setting versus hospice or comfort care only. Their perception concluded that despite length of time under an oncologist care, this transition was disjointed, unpredictable, and produced a feeling of abandonment from their loved ones primary oncology team.

Table 22: Examples of Support from DPR Participants

Examples of Support from DPR Participants		
Themes	Categories	Exemplars
	Caregiver/DPR support	"So, I think 3 months before she died, he stopped working. Uhh, he took off six or seven months in total about three months before and three to four months after. And, umm, was home, was home with them. Home with the kids. Home with her, all the time." (14)
	Support from other cancer patients	"Umm, she was involved in at least two, umm, local like online groups, maybe just one. I can't remember. But I think it was two though." (2)
	Family	"She was in [hospital name] hospital at the time and umm, she went

Sources of Support	(immediate)	there and stuff. And my dad took her over and stuff to the ER and everything and stuff. Afterwards, she had her hospital room and stuff and umm, the staff was really nice, but my mom didn't really, she didn't like the food or anything. And, but she was like a bit upset about that so she would ask us to bring other food and stuff. So, we did that to like help out and sort of thing and stuff." (3)
	Family (extended)	"We knew, we knew what was in store, and I was a little hesitant to tell her. But she was weakening so… and there, there were members of the family who came over to help me and, uhh, we talked about hospice and, uhh, but I, was a little reluctant to go to the hospital bed part. And, uhh, I…we walked her into the room where the hospital bed was and she said, "oh, that's a good idea, you know, for lowering and raising it. I, I think I would be more comfortable on that." And that was the end of it. She went over to the bed right away and she was conscious up until the last day or two." (26)
	Healthcare Team	"Yea, I thought they were very kind to her. [Treating oncologist] had a physician assistant who I thought was just extraordinary, just exceptionally fine in terms of making sure that all of her needs were being met, and listening to any concerns she might have, and asking for concerns." (24)
	Friend support	"And that was, that was [patient's name] wish. And a handful of my real close friends knew and umm they were writing wonderful notes to [patient's name] encouraging her, and saying how "we love you," and, you know, how "we are rooting for you," and "hopefully things will turn out all right," and all that sort of thing. Umm, she had, she had, she has, she has as much support as she wanted. She just didn't want to engage a large circle of friends knowing that she was gravely ill." (24)
Types of Support	Absent (perceived)	"There were a couple that were really good except the head, uhh, of the cancer department. I can't remember his name…Dr….umm, hmm. He just seemed like he was more interested in…umm, oh, how could I say it? Speaking and writing miracles." (8)
	Financial	"Umm, well. [patient] had cancer for a long time. She had cancer for 8 years before she died. And [treating Oncologist] and his staff were very good at getting her into all kinds of trials so that she could get medications (cough) that were not yet officially approved for wide use. They were also instrumental in getting her…she was self-employed – she was an entrepreneur…Umm, her healthcare for her cancer treatment through a foundation. I forget the name. But they were amazing. So [patient] paid nothing for her treatment." (6)
	Spiritual support	"So, I would say that [patient]…and me I suppose…but [patient] specifically - we both have a lot of friends with our church and in other places and so we processed it through those, umm, those support groups." (2)

"Most definitively. That was a…her, her uhh, her uhh, her belief was a big deal. I mean, her, her religion and everything was a big thing to her." (17) |
| | Inappropriate (perceived) | "So, during that whole time, I had reached out to, umm, the oncologist she had at the end was also a [clinic name] doctor, Dr. [second oncologist]. And every time I would call his office, he would send me to another-and I don't know what the name is, it's basically social care part of [clinic name] - they were not very helpful. And I realized as oncologists you have thousands of patients, you are extremely overworked but the handoff from the doctor to the social workers without any explanations and a lot of times the oncologist require, like |

| | | their nurses that they deal with, to pass on the interaction, and that wasn't happening at all. So, we had weird things happen with- I don't know what it is- some sort of social network for people who were like suicidal-come to our house one day. Umm, you know, they were making attempts to help but the help was so off base that it wasn't helpful at all. It was actually the opposite." (22) |

Knowledge

Finally, the means of gathering knowledge, preferences for knowledge type, past experiences and their influence on the current experiences, and negative outcomes when knowledge was lacking (i.e., missed opportunities, misinformation, limited knowledge provided, and the burden of knowledge) played a significant role both during the disease and treatment course but how the DPR was able to cope with the loss of their loved one.

Table 23: Examples of Knowledge from DPR Participants

Examples of Knowledge from DPR Participants		
Themes	Categories	Exemplars
Initiators of knowledge exchange	PT-driven or DPR-driven	"So, she, she very much started to research things on her own through different sources and things like that and so one of the ways that she processes information, or she processed this area- was through information gathering. And, umm, and looking through reputable sources. So even outside of the doctors and stuff that she would deal with, she would already have a lot of information whenever she would go to a doctor's appointment because she had already done a lot of the research on her own." (2) "So, I would specifically have to call the oncologist, then go through the nurse and go through all these hoops because like I said, she really wasn't under [second oncologist] care, and he would visit because he would do office hours, or you know, he would do rounds at [hospital], but I would try and get it so that we were all three there. And, you know, doctors don't care about your schedule but I would just say, "tell me what your schedule is and I will make myself available." And it felt like they avoided it." (22)
	HCP-driven per the DPR	"They had the initial appointment where they expressed the concerns, once, once there was uhh, once the doctor, I think, clued into what they, what the potential was. They, uhh, they were sort of prepared for a diagnosis, but they didn't expect umm, the…that it was already stage IV, that it was metastatic. Umm, and, uhh, you know, they, they were in so much shock. The first doctor that diagnosed them, is not who treated…he was not the oncologist she ended up staying with…" (14)
Burden (of)		"There were things that were sort of undone for them. Umm, when she got to the point when, you know, she couldn't get out of bed; umm, was having fevers, you know, the kids are having to call 911. Umm, that was the stuff that weighed heavily on her." (14)
Misinformation		"…it's something that has bothered me greatly but she never knew about it. Umm, which is that, she decided to will her body to science because of

		the rarity of her type of cancer. She wanted them to be able to study it. Umm, and she went through the process; she did the paperwork - the [university location] has a will body program - she donated her body to science; I signed the paperwork with her. Umm, what they did not tell her and I learned after her death when I - because I work at [university location] and I know the will body teams and so I called them and I was like, "you've got my sister-in-law." umm, but, but they, that if she wanted her body to go someplace specific, she would have had to arrange that prior to her death. And, umm, so there was no way to, to specify after her death where her body would go and what it would be used for. And this has particularly become an issue because she had long talks with her children about the fact that they wouldn't be able to cremate or bury her or have a celebration for her until her body came back because she was out doing – letting them do this work with her cells." (14) "And her cell type was misdiagnosed. And that doctor later, umm, he left and he was went to another hospital and had some legal troubles. I think, like he was a complicated guy. So, by the time we got to [treating Oncologist]'s office, it had been...it had been too long." (6)
Preferences for		"Yeah, whether, whether that's totally factual, I can't tell you that because I can only tell you, what I, what I perceive to have happened. And what I perceive to of happened is that everyone was happy day- maybe with good cause, maybe that's the right thing to do, I don't know- I just know that - when it's all over and you're left… you evaluate everything that happened, you start to going, "they could have... and, and, and so I would tell you exactly what [patient] would say because I had this conversation with her. She would say "ok, let's say they had been doom and gloom, what would we have done different?"
Past Experiences		"Umm, yeah, but not specific to breast cancer. But specific to long term chronic illness, yes. My stepmother had Alzheimer's, my stepfather had Alzheimer's – uhh, both of those two are long term degenerative diseases. I mean, people, yeah, they go downhill over a long, long, period of time and so, yeah, to watch that process happen before it ended- to watch the experience of my mom in the case of my stepdad and my dad in the case of my stepmom - certainly that was complicated. And then, umm, my mom passed away, she had a, she had a sarcoma on her leg and, umm, so she had whatever treatment she had for that. She had a surgery, radiation treatments, and all that kind of stuff and then eventually she passed away from her sarcoma that spread to her lungs. Yeah. So yeah, we have, umm, I would say from a chronic illness perspective, then those would be the three that are the most, uhh, I think that would be most illustrative of what you're talking about." (2)
Missed opportunities for communication as well as knowledge		"So, uhh. That was – whether it was from Dr. [treating Oncologist]. I don't know, she was trying to always be optimistic, but again, at some point, we need to uhh, to you know, face, face the issues. I think maybe when we got near the end we did, but unfortunately, when it came up, when it finally came about, it was quick in the sense, that she, uhh, went kind of went into unconsciousness and, uhh. So. You bring up some sad memories, but uhh, I didn't really have a good chance, in my mind to say goodbye *(slightly choked up here),* the way I wanted to…" (9)
Limited knowledge		"And I'm just using the EOL type experiences, once… so she had that surgery in 2019, I don't think it was really explained, and I don't think they really knew how, how bad it was going to be. And then, it never healed so, so they basically said that she had so much radiation and so many surgeries that, that was why. But thinking, that if she had known that or if they would have told her that, that was a possibility, she may not have had

		it." (22)

6.5   DISCUSSION

Throughout the MBC diagnosis, disease progression, EOL, and death, the care needs for both the DPR and their loved one can dynamically evolve (Aranda et al., 2005; Sudore & Fried, 2010; Vilhauer, 2008). Within each of these transitional stages, patients and their DPR can experience a combination of met and unmet needs (Mayer, 2010; Moghaddam et al., 2016; Rainbird et al., 2009; Vilalta et al., 2014). Within this DPR cohort, four major categories emerged as primary priorities essential to high quality EOL care, that is resilience, communication, support, and knowledge. In order for the DPR and, by proxy, their loved one to have experienced a perceived high quality of EOL care, it was important that these categories were integrated together through the disease progression and treatment course. While these areas could have alternating levels of importance given the unique situation of the DPR and their loved one at any given time, the idea of high-quality care at the EOL was achieved if they had perceived the presence of these categories when needed. If one or more categories was perceived as lacking, then the DPR or patient would often count their EOL care as poor quality and attempt to compensate for its deficiency. For example, if minimal healthcare team support was perceived to have occurred, the DPR or patient was then subsequently driven to seek out their own knowledge regarding the disease or treatment care options. On the other hand, if the DPR perceived that both the communication and information presented by the healthcare team was honest and complete in content, there was little motivation to seek alternate sources of information or feel as though the care received was dissatisfactory. However, if the patient or

DPR felt inadequate to seek information personally, they would often regard this component of care as frustrating with little understanding on how to control their disappointment or communicate this deficiency.

In line with previous research, this data also recognized that while there is an extraordinary number of healthcare providers that make up a single patient's healthcare team throughout the course of treatment, individual healthcare providers continue to exert a profound, distinctive influence (Chung & Carlson, 2003; Niranjan et al., 2019; Sheppard et al., 2011). For example, in this cohort, those healthcare providers (i.e., nurses, advanced practice providers, oncologist, and/or consulting physicians) who consistently displayed the characteristics of kindness, genuineness, and demonstrated that they were "not in a rush" became sources of comfort and reliability for both the DPR and patient, regardless of length of care. In contrast, healthcare providers who were perceived by the DPR to be abrupt or lacking in compassion towards the MBC patient, had a negative impact on how satisfied they felt about the diagnosis and their ability to achieve goal concordance. Furthermore, in some cases, when the DPR perceived the patient was no longer "interesting," they felt their primary oncologist, regardless of years of care, "abandoned" the patient at their EOL when interventional treatments were no longer required. Significant loss of relationship and ensuing frustration often accompanied these situations. While these experiences may be uniquely confined to this MBC cohort, communication, including compassionate, hopeful, honest conversations, is a crucial component of high quality care, particularly at the EOL (Butow et al., 2014; Mack et al., 2009; Stajduhar et al., 2010).

While a large percentage of the deceased MBC patients experienced one or more of the poor quality EOL care indicators, there was not a significant amount of distress over their

occurrence. This reinforces the idea of a shifting paradigm in what is considered high quality EOL care from previous perspectives (De Schreye et al., 2017; Sanders et al., 2018; Wright et al., 2016). In fact, in many cases, continuing chemotherapy or using acute care services was in concordance with the patient's wishes, as described by the DPR. This may perhaps indicate that patient and their providers could have different preferences or priorities throughout the disease and treatment course, which became highlighted at the EOL (Rocque et al., 2019). However, it is vital to consider whether or not the patient, at the time of each decision-making moment with the healthcare provider, was completely informed on the disease progression and whether or not alternative options were available.

Finally, it is important to note that although the DPR never technically had an MBC diagnosis, they often uniquely feel the effects of its burdens. Therefore, the lived experience of the DPR, in conjunction with their loved one, is vital to acknowledging as its influence will continue far into the future. While there were several DPR participants who regretted their perceived lack of information or lack of clarity in which information was shared, there was never a DPR, whether for themselves or in proxy for the MBC patient, who shared that healthcare providers were too honest or too truthful about the realities of MBC. In fact, those who felt they had received complete information about the disease and treatment course were thankful for the acknowledgement of the difficulties, able to successfully transition and adapt throughout the disease course, and seemingly the most well-adjusted after their loved one passed away.

6.6 CONCLUSION

While the heterogeneity in treatment response and overall length of survival will continue to vary according to subtype for patients diagnosed with MBC, there are significant components of care that seem to have a more marked effect on the patient and DPR. Role and care transitions for both the DPR and the patient were vital in promoting their resilience regardless of current treatment components. Additionally, for most DPRs, preparation, saying goodbye, following their loved one's wishes, and both understanding and being understood were vital to the care process.

6.6.1 Strengths and Limitations

There are several strengths to this study. First, the DPR group that was interviewed were composed of several different geographical locations, with a subsequent variation in external influences (i.e., financial variation, support system variation, etc.). Secondly, this patient group was treated by over five different oncologists with an array of treatment strategies, communication pathways, and referral processes. We do recognize, however, that while there are a number of care variations, there are minimal differences between racial, relational types, and education statuses amongst the DPRs themselves. A more diverse DPR population could perhaps illuminate additional care considerations currently not delineated at present.

7.0   DISSERTATION MANUSCRIPT 4: MIXED METHODS

7.1   ABSTRACT

Background: Due to the heterogeneity in treatment response and overall length of survival for MBC, it is vitally important to individualize treatment and care goals. One of the methods for individualization is having GOC discussion at diagnosis and throughout the patient's treatment course. However, there can be several burdens, barriers, and facilitators within this communication process unique to the MBC population. As the full experience of DPR personal representative must retrospectively act as a surrogate to understand the patient's experience and wishes in comparison to the treatment actually received. Therefore, the aim of this study was to examine the quality of death and dying as measured through the QODD survey responses from the DPR.

Methods: This study is utilizing an explanatory sequential quantitative - qualitative mixed methods design with independent data analysis conducted. The DPR was recruited from the following settings which included, 1) a southwestern Pennsylvania cancer clinic, 2) a regional cancer support group, and 3) two social media group platforms. Participants included in the analysis completed both the QODD survey as well as a telephone interview. The designated point of interface for quantitative and qualitative data occurred at the results point of integration. With each category of survey responses and experiential groupings made from the QODD survey

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question related to EOL care wishes, the interview content regarding EOL wishes and GOC discussions were added and integrated.

Results: In response to the question, "did your loved one discuss her wishes for EOL care with her doctor?," 75% (n=12) answered "yes," 18.8% (n=3) answered "no," and 6.2% (n=1) answered, "I don't know." While the majority of survey responses reported that "yes" (n=12; 75%), patients were able to discuss their EOL care wishes with their physician, and that this was an above average experience (n=8; 66.7%), the comments and perceptions surrounding such conversations were somewhat incongruent with the quantitative data. When asked to describe these conversations further, the DPR considered them unsatisfactory or extremely limited in content, focusing more on care decisions rather than prognosis. The omission of any prognostication on the part of the physician, ultimately left the patient and DPR without clear direction. Furthermore, upon reflection by the DPR, this lack of direction was more burdensome than anything else.

Conclusion: The perception surrounding the quality of care received at the EOL can vary for each patient and DPR. It is vital to ensure that goal concordance is discussed long before EOL is required with both the patient and the DPR.

Keywords: metastatic breast cancer, end-of-life care, quality of death and dying, goals of care discussions

7.2   INTRODUCTION

Metastatic breast cancer (MBC), with its complex treatment course and potential side effects, can challenge the patient, provider, and the DPR with how best to individualize care for those who have received such a diagnosis and are embarking on a treatment course. Much of this assessment with the current system processes in place, can unfortunately occur only after someone is deceased from MBC, as their full course of treatment and the actual EOL care received can only be known and fully assessed at that time.

At diagnosis and in the process of receiving advanced cancer care treatment, the patient and DPR should be participating in a GOC discussion, by which their healthcare provider (HCP) discusses the patient's prognosis, treatment options, expectations, EOL care planning, and patient wishes for future direction of care (Levit et al., 2013; Schulman-Green et al., 2018). According to the American Society of Clinical Oncology (ASCO) consensus guideline, GOC discussions should be completed at diagnosis, with each relapse or progression, change in treatment approach, and at patient/family request and be iteratively revised throughout care for clarity in disease prognosis, treatment concerns, mitigating symptom burden, and preparation for EOL care (Gilligan et al., 2017).

There have been tremendous strides within the MBC care realm integrating palliative care and GOC discussions with patients and their families. There still exists current patterns of miscommunication or even lack of communication between healthcare providers and their patients, patients with their DPRs, and DPRs with the healthcare providers. The disconnect found within these lines of communication has, in turn, given rise to poor-quality care as manifested by a perpetuated lack of preparedness for death by both the patient and DPR and potentially prolonged treatment-induced burdens.

By speaking as a surrogate, the DPR can give tremendous insight into the burden, barriers, and facilitators to the quality of EOL care. A thoughtful analysis by the DPR allows a reflection of the patient's EOL experience and its congruence with their wishes. Therefore, the aim of this study was to examine the quality of death and dying as measured through the QODD Survey responses from the DPR and the qualitative interview.

7.3   METHODS

Study Design, Sample, and Setting

This study is utilizing an explanatory sequential quantitative - qualitative mixed methods design with independent data analysis conducted.

The primary setting was at a southwestern Pennsylvania cancer clinic, which serves as a multidisciplinary center dedicated to both the research of and treatment for MBC. The DPR cohort from this primary setting was collected using an established clinical database for patients deceased from MBC. The deceased MBC patient's name, birthdate, and date of death was received from the clinic. Using those data, the contact information (i.e., name, address, and email) of the DPR was retrieved from the EHR. A letter was then sent requesting the decedent's DPR to participate in the study through a Qualtrics-provided link for the QODD survey, with a subsequent option to be recontacted for the qualitative interview.

The secondary setting was through a regional southwestern Pennsylvania cancer support group for DPRs, and two social media group platforms whose focus is specifically within the MBC population. For the regional cancer support group, *The Cancer Caring Center*, and social medial group platforms, *Young Survivor Coalition* and *Metavivor*, the snowball sampling method

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was utilized. Ultimately, it is unknown how many participants were contacted through these methodologies. While *The Cancer Caring Center* is a general cancer care support group, the leader of the support group was provided an overview of the study from the PI. Information regarding the study was provided to the support group members in the form of a letter, with each participant conducting self-selection for eligibility and subsequently accessing the QODD survey. For both social media groups, inclusion and exclusion criteria were provided via a social media announcement for the participant to self-select their eligibility with attached instructions for accessing the QODD survey. In each of these recruitment groups, there was also the option for the DPR participant to complete the survey over the phone or on paper due to physical limitations. If completed in either of these ways, consent was obtained verbally prior to completion.

After the QODD survey was completed and permission was granted to recontact for the telephone interview, the DPR was then directed to list two convenient days and times for interviewing. The PI, after receiving contact information availability, reached out to each DPR. For those DPR participants who completed their QODD survey over the phone with the PI, the qualitative interview directly followed, or an additional day and time were agreed upon. Verbal consent was obtained prior to each interview. For those DPR's who did not respond initially to the first phone call, a second and final phone call was conducted by the PI.

Data Source/Data Collection

Each participant who took part in a telephone interview was categorized based on their QODD survey response regarding whether their loved one was able to discuss their EOL care wishes with their doctor. The responses could either be, "yes," "no," or "I don't know." After each participant was categorized according to these responses, they were then further subdivided

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into how they rated this experience (Sandelowski, 2000). The experience could be rated from 0-10, with 0 meaning "terrible" up to 10, meaning "almost perfect." Using the majority category, those DPR participants answering "yes" to the QODD survey question of interest, the experience scores were divided into three quartiles (Marshall & Jonker, 2010). Based on the median value of 8, the following groupings were then formed as scores of 0-6, scores of 7-9, and scores of 10. These categories were then used for each type of QODD survey responses. Finally, the PI then examined the DPR's interview responses regarding GOC discussions and EOL wishes for complementarity of survey responses.

Analysis

The designated point of interface for quantitative and qualitative data occurred at the results point of integration (Morse, Janice M. , and Niehaus, 2009). With each category of survey responses and experiential groupings made from the QODD survey question related to EOL care wishes, the interview content regarding EOL wishes and GOC discussions were added and integrated.

7.4   RESULTS

Within the QODD survey, each respondent answered the question, "did your loved one discuss her wishes for EOL care with her doctor?" The participants could answer either "yes," "no," or "I don't know." Of the data collected from all of the DPR participants (N=25), 68% (n=17) answered "yes," 24% (n=6) answered "no," and 8% (n=2) answered, "I don't know," for the QODD survey. However, for those DPR participants who took both the survey and completed

the qualitative interview component (N=16), Figure 4 illustrates the distribution as 75% (n=12) answered "yes," 18.8% (n=3) answered "no," and 6.2% (n=1) answered, "I don't know."

Figure 4: Quality of Death and Dying Survey Responses
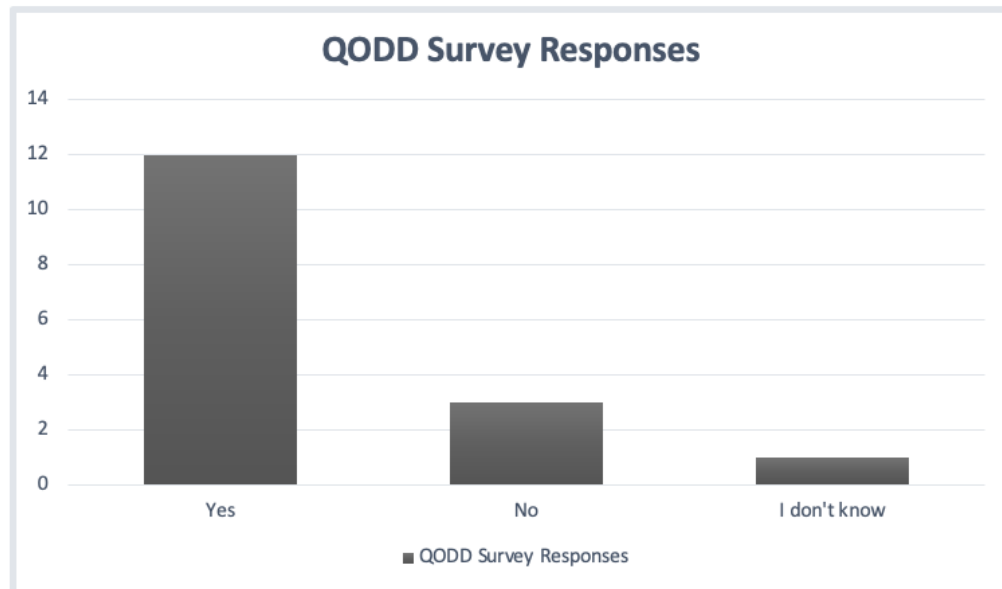
Using results point of integration, Table 24 presents a joint display of both the QODD survey responses in combination with the DPR's experiential rating of the conversation to then match it with content discussed during the qualitative interview. The experiential rating was scored between 0-10, with 0 meaning a "terrible" experience and 10 meaning an "almost perfect" experience.

Table 24: Results for the Point of Integration for QODD Survey and Interview Responses

Experiential Score	QODD Survey
	Question Response: "Yes"
0-6 Score	"…he would always say, " well, you know, I think we should try this, or you know, I think we should give this a try, or you had this before but let's try it again now." Always, like, like, like there was hope. He never, errrrr, like "let's try." You know, he never, uhhh, evaded to the fact that like, "well, uhhh, you know there is not much more we can do, you know, but keep you comfortable, or whatever." We never, he never even got to that conversation. Should that have been? I don't know. Who am I to say?" (12) "No, no. It wasn't that. It was like some lady on the phone and I know that person was a staff member at [treating Oncologist]'s office. But she wasn't someone that [patient] knew and it certainly wasn't Dr. [treating Oncologist]." (6) "But the exact words I remember were, she said, "I think it's time we start looking at the big picture." Them exact words. Which I took that to mean, "in other words, we are getting near the end here. You know. Uhh…uhhh, we never got anything like that specific from the doctor. So, the doctor, yeaaa…I don't want it to sound like I'm talking bad about him, because that is not my intention, but it was short and sweet when the doctor come in. To answer your question." (12)

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	"No, no. Because like I said, he doesn't…he's not that person. He's a positive, positive influence. And, I mean, he was always uhhh, he was always looking for a way to make it better. No, he was actually very upfront about everything. I mean, he was always, you know, "this is what's going on, this is what we're doing, this is what we're trying." And I mean, he was always, uhhh, you know, he always tried to keep you abreast of everything that he was doing." (17)

"Well, uhh, we kind of took what we were offered. Uhhh, you know, it wasn't what we – we know nothing about this, so, uhhh." (12) |
| 7-9 Score | "So, I think, it could have been just a regular appointment or just one meeting to discuss, "hey, this is what's on the table." Whether it's uncomfortable for everyone or not, it just needed to be a set time that never really happened. Like I said, he did visit her without me there and I would talk to him on the phone and say, "this is what we need to discuss" and he would talk about a clinical trial in June. And I was like, "that's false hope." We don't need that. We don't need that kind of fluff. We need more reality diagnosis." (22)

"Sure, ummm, I would say maybe they did happen, but they weren't really realistic, or it was just "check a box" type of thing."

"Throughout her entire treatment she was able to do that with Dr. [initial oncologist] but limited with Dr. [second oncologist]. Mostly because there weren't as many things available and she had already been in clinical trials and things like that, so they weren't as willing to put the time in knowing that you were in them, and you weren't as successful."

"So, I would say, I would say no. It never got to the point. No, I can, I can guarantee you that it never got to the point where Dr. [treating oncologist] office says we don't have another option after this one. There was always, umm, we're, we're going to try treatment X. If treatment X doesn't have an impact then we're gonna try treatment Y. If treatment Y doesn't have an impact then we will have Z. So, it was always, umm, ok we're doing X now and don't worry about it if this doesn't work we've still got, we've got a whole lot of- whatever, we have 15 more things we can, we can try. So, there was never the point that they said, "look it's time to start prioritizing how you're, you're living your life. Go on you need to start working on your bucket list." It was not that." (2) |
| 10 Score | "Umm, we talked with the clinical staff, of course, we have, we have end of, EOL, uhh, documents that we sent to the hospital and we didn't – neither of us wanted any, uhh, any, uhh, aggressive care treatment at the end." (26)

"Uhhh, *(pause)*. I don't know if it came up for treatment appointments a lot. We um, I mean, we had our own conversations about EOL so one of our trips was to go over in another town maybe 30 miles away and update our will, living will, whatever, we wanted to make sure we had it up to date and get her final resting place. *(Chuckles)"* (4)

"…there have been a lot of discussions that I have had with the oncologist. Ummm, even outside of her presence. So, part of the reason he was picked was because he was young, and he was willing to sort of think outside the box a little and suggest things. So…but he was very honest with her about the odds, given the rarity of her type. The odds weren't…she was going to die early." (14) |
| Question Response: "No" | |
| 0-6 Score | "Umm, maybe that would have…if they brought it up [GOC discussions], maybe that would have ushered in, uhh, some conversation from [patient] how she was feeling and what she wanted, you know, me to do. It was gonna be…like her and I. I, I still can't believe…it's been, uhh, 13 months and I still can't believe that she's gone. I really can't." (8) |
| 7-9 Score | "You know, [patient's daughter] was complaining to me about not knowing what was going on. And I said, "honey, it's probably because nobody really knows." It's not black and white. Umm, I think she was thinking that we should have been better informed on what her status was." (24)

"She did not, she did not and that always, you know, it's almost like you wanna be an ostrich with your head in the sand. It's like, you don't want to hear those words, but retrospectively would it have been better if I had? Probably." (25)

"Mmm, you know, it's interesting. Ummm, there was never any conversation about going home because I, I think what was in the back of her mind was, "I want them to do what's best for helping me get better. I'm so, if that means that I need to be in the hospital or if I have to be in the emergency room or if I have to have, you know, this, that, or the other thing, then so be it."

"No. None. She just followed the doctor's orders."

"It's almost got to be like a soft sell. It's, it's gotta be like, hey, this is reality. Cancer is a crummy disease. Some people beat it, some people don't. You know, we are getting closer to cures all the time – you gotta – you know, I'm in sales, you gotta kind of build it up a little bit. And say, face reality a little bit, but it's gotta be done in a, in an incredibly compassionate way. Ummm, and you gotta leave the clinical part away from it. And that's not not easy to do, I recognize that. You know someone hands you a book like, "this is what you can expect in the final hours of death," it's like what are you guys telling me here? Are you guys giving up? Is she gonna die? You know… you might realize that eventually in the back of your mind, but you're not thinking that at the time. So too kind of prepare people in kind of- in the best way possible- and, and you know, God knows I don't know how you do that. I don't know how you do that. But it might have been easier on me and my kids and maybe even her, you know."

"He was candid. He said this is a very grave illness and she is close to the end perhaps, we don't know. Umm, but it's quite likely, she may be gone, you know, in a short period of time." |
| 10 Score | n/a |

Question Response: "I don't know"	
0-6 Score	"Umm, I, umm…yeah I would say, based on, yeah, based on like how I remember everything, it was more or less like had like the… where we happen to like, you know, deal with all of her kind of like goals of care sort of thing and stuff. Cause it kind of came like a shock like with um, with umm, my dad and my uncle Timmy who was there, umm, especially and everything and stuff. And umm, you know, umm, cause they were very shocked. They were very stressed out about like… what are we going to do? Like that sort of thing and stuff and I was shocked too and stuff, but I was more shock cause like from the perspective of like, you know…uhh, you know, I wasn't realizing that this was going to be happening now, you know, that sort of thing. Umm, same, same, same with my aunt and stuff too. Umm, But she's coming she's someone that could always keep a levelheaded about everything- that's just her personality- but I mean, I remember like, umm my… cause my aunt Mary and my mom, like they talk like a lot like on the phone and that sort of thing and stuff. So, like they were pretty close in like talking about like you know, stuff like that. So they were, you know, pretty close in like knowing like you know what, what, you know, either one of them would want you know if something sort of happened sort of thing. And umm, Timmy, Timmy, not really cause he was like, he's off doing his own thing sort of thing and stuff. My mom would try to reach out to him and stuff but sometimes he wouldn't be, he wouldn't be able to talk with her and everything and stuff. So, it was just kind of hard with him. Umm, my dad, she, she would tell some stuff but umm, I feel like she told me more than my dad cause like, I feel like she trusted me more of being like being a responsible, umm, like person to have like take care of stuff. Cause my dad gets very emotionally upset about a lot of things and umm, I feel like she didn't, she didn't feel like she could have that conversation with him because you know she wasn't sure like you know, how he would react sort of thing, you know?" (3)

"I mean, I, I certainly, umm, you know, would have wished to have like some of those like you know some of those conversations cause I really, you know, I really didn't know as much. Like I basically knew like you know like she's, she's you know like fighting the disease and everything and I knew like she's taking her medication and doing different therapies and stuff to try and fight the disease and stuff, but I didn't really know like how, how she was doing. What was going on and everything and that sort of thing. Umm, but you know umm, but I feel like for her I mean, I, I guess you know, that could have helped but umm I also feel like it could have made, umm, you know, her anxiety a little bit worse you know, just because you know, she's like…it's getting worse, what am I gonna do? Like that sort of thing like I can see her stressing about that in my mind and she may have been like that if her doctors did tell her, you know. Umm, I, I don't know if, if they told her that or not, I honestly don't know but I, but yeah she's, she's usually stressed out though trying out new medication and stuff so maybe they did try to tell her and stuff and maybe she's like you know felt like she had to go on with it and stuff because she's trying to fight it for both like my dad and myself, you know." (3) |
| 7-9 Score | n/a |
| 10 Score | n/a |

7.5   DISCUSSION

While the majority of survey responses decidedly reported that "yes," patients were able to discuss their EOL care wishes with their physician, and that this was an above average experience, the comments and perceptions surrounding such conversations upon further reflection by the DPR may not sufficiently support their above average rating. This would suggest that perhaps there was a discrepancy between what the DPR initially perceived the "end-of-life wishes" of the patient were and the definition provided by the interviewer describing end-of-life wishes and care. Additionally, the time between when the surveys were conducted and the interviews completed were varied and could have influenced how the DPR thought about their loved ones EOL care wishes and experience. Regardless of these potential discrepancies, when

the EOL care experience was assessed, the DPR often felt that these conversations were still lacking in content, conducted too far into the disease progression, challenging to bring up with healthcare providers, and perpetuated their inability to prepare for the eventual loss of their loved one. These barriers, unfortunately, have continued (Brooks et al., 2017; Connor et al., 2002; Nedjat-Haiem et al., 2017; Nedjat-Haiem & Carrion, 2015).

For those who reported that "no" they did not have any discussion regarding EOL wishes or care, there was a perceived lack of direction or expectation with how this type of information would have been relayed during care. This lack of preparedness or direction could perhaps make the passing of their loved one, although diagnosed with a terminal disease, feel as though sudden and therefore, more traumatic (Odgers et al., 2018). Upon further reflection, some DPRs felt unprepared both before and after the patient had passed away while others admitted to their lack of desire in wanting to know the truth. In many cases, however, while the DPR acknowledged that they did not want to ask for the "difficult information," there was often a communicated disappointment towards the healthcare provider when the prognostic and GOC discussions were not initiated (Bussmann et al., 2015; Kisorio & Langley, 2016; Steinhauser et al., 2015). This may indicate that the DPR, and by proxy their loved one, may ascribe a different level of importance to certain parts of EOL care and discussion components than the healthcare provider.

Ultimately, it was when the DPR perceived honesty and truthfulness from the healthcare provider, and relaying information about the EOL or instigating a GOC discussion, that the DPR felt relieved and was the most satisfied with the EOL care received. It was also important to the DPR that they perceived the patient having received all the information they, the loved one, had wanted, even when it wasn't ideal for the DPR (Clayton, Butow, & Tattersall, 2005). In those

instances, the DPR wished that there was a separate mechanism of information delivery for their own benefit in caring for their loved one.

In general, whether satisfied or dissatisfied with the EOL care received, the DPRs did not seem to take issue with the experience of poor quality EOL care indicators. For example, for those who had received hospice care, whether several months, several weeks, or several days prior to death, it did not seem the preference of the DPR to have received their services for a greater period of time. Additionally, for those patients who used ER services or had hospital admissions prior to death, it did not feel burdensome, but was a relief to have additional care provided to their loved one at the EOL. However, further investigation is required to explore whether the utilization of these acute care services is a shift in the patient's treatment preferences or an indication that there still exists misunderstanding about the non-curative nature of MBC (Weeks et al., 2012; Wright et al., 2008).

7.6   CONCLUSION

As previously noted, there is an apparent variation in responses which could be due to several factors. First, it is unknown whether deeper questioning during the qualitative interview regarding the EOL care received brought forth forgotten experiences that were not remembered previously during the QODD survey responses. Secondly, it is possible that the DPR's were reflecting the perceived patient's experience in the survey but their own perspectives during the interview. In addition to what has been learned previously in the qualitative analysis (i.e., the themes of resilience, communication, support, and knowledge), GOC discussions and

maintaining good communication between the healthcare team as well the patient and DPR, remained an essential component of high-quality care. Therefore, in moving forward with the healthcare stakeholder feedback group, it will be vital to present the DPR's perspective of a GOC discussion, QODD survey score responses related to EOL care wishes, and important themes noted in the interviews for a meaningfully focused stakeholder feedback. Focused presentation objectives will include, 1) the perceived influence of experiencing any of the poor quality EOL care indicators for women with MBC, 2) clinic and staff loyalties from both the patient and DPR, even after the patient has passed away, and 3) limitations surrounding GOC discussions.

7.6.1 Strengths and Limitations

There are several strengths to this study. While primarily centered around one facility, the MBC patient and DPR cohorts are collected from five different states and over five different individual oncology providers which gives variation to EOL care experiences. However, we acknowledge that there are a few limitations with this study, particularly related to the smaller sample size. If taken from a greater pool of participants, the distribution of frequency and experience survey scores could be different than what is currently presented for this study.

8.0   DISSERTATION MANUSCRIPT 5: STAKEHOLDER FEEDBACK

8.1   ABSTRACT

Background: With the establishment of quality EOL care standards, the treatment team serves as the means to deliver EOL care and may be diverse in specialties and expertise. While working within individual specialties to provide care, collaboratively, the team is essential for providing knowledge around 1) diagnosis; 2) anticipatory guidance for disease management; 3) assistance in navigating insurance and financial needs; 4) any competing social and personal needs; and 5) EOL care planning and implementation. Given the complex nature of orchestrating care, it is important to provide a concerted care plan that maintains high quality EOL and goal concordance with the patient's wishes. Therefore, the aims of this study were to present the results from 1) a retrospective chart review delineating women diagnosed with and deceased from MBC who were most at risk of receiving poor quality EOL care (Earle et al., 2003), 2) the QODD survey giving to DPR of women deceased from MBC, 3) a qualitative semi-structured telephone interview with DPRs after completion of the QODD survey, and 4) the mixed-methods study results focused on GOC discussions to a group of MBC multidisciplinary healthcare providers for stakeholder feedback and EOL care process suggestions.

Methods: After the findings from studies 1, 2, 3, and 4 were integrated with the current best practice guidelines, the PI attended an established meeting with all of the designated

clinician groups to present the coalesced information. Focused questions were then directed towards the clinicians regarding their opinion of the presented guidelines, implementation strategies, feasibility of practices, and integration within their current clinic practices. The meeting was recorded and transcribed by the principle investigator. Keywords and themes were captured and integrated into best practice recommendations for metastatic breast cancer patients.

Results: The stakeholder feedback group reported several barriers to achieving meaningful GOC discussions during the trajectory of MBC care. These barriers included individual providers (i.e., communication difficulties, provider resistance, lack of training), system-wide issues (i.e., clinical time allotment, charting inconsistencies), and current widespread beliefs regarding the nature of metastatic disease.

Conclusion: Presenting this comprehensive, multifocal viewpoint of EOL care of women deceased from MBC back to the HCP with whom the treatment was conducted can allow for the development of targeted and meaningful approaches to EOL care for women currently diagnosed with MBC.

Keywords: metastatic breast cancer, stakeholder feedback, provider's perspective, quality of end-of-life care, goals of care discussion

8.2   INTRODUCTION

End-of-life (EOL) care standards have been established, and recommendations provided to address the unique care needs for advanced cancer patients by several national organizations. The National Institute of Nursing Research (NINR) and its Office of End-of-Life and Palliative Care Research (OEPCR), as well as the American Society of Clinical Oncology (ASCO) have advocated for the priority of integrating palliative care within chronic care treatment plans, assisting with clinical decision-making between patients and healthcare providers, relieving burdensome symptoms and suffering for those diagnosed with a life-limiting illness, and establishing quality indicators for EOL care and a good death (Bakitas et al., 2009; Ferrell et al., 2017).

While those sweeping standards and recommendations are useful for advanced cancer care in general, the EOL care needs for the MBC population are unique and make the care delivery team vitally important. The treatment team serves as the means to deliver EOL care and may be diverse in specialties and expertise. While working within individual specialties to provide care, collaboratively, the team is essential for providing knowledge around 1) diagnosis; 2) anticipatory guidance for disease management; 3) assistance in navigating insurance and financial needs; 4) any competing social and personal needs; and 5) EOL care planning and implementation (Funk-Lawler & Mundey, 2020; Krigel et al., 2014; Reiser et al., 2019a).

In addition to the interdisciplinary team members and their care dynamics, several challenges remain for meaningful integration of high quality EOL care for women with MBC. Some of these challenges can include, 1) the timing of the integration of meaningful EOL care, 2) variability in tumor subtype, (El Saghir et al., 2011; Kennecke et al., 2010; Laohavinij et al., 2017), 3) disease prognosis, (Johansson et al., 2019; Lobbezoo et al., 2013; Nahid Nafissi, 2016),

4) treatment options, (El Saghir et al., 2011; Peppercorn et al., 2008), and 5) patient and family characteristics and expectations (Bernacki & Block, 2014; Chung & Carlson, 2003; Hancock et al., 2007). Therefore, the aims of this study were to present the results from 1) a retrospective chart review delineating women diagnosed with and deceased from MBC who were most at risk of receiving poor quality EOL care (Earle et al., 2003), 2) results from the QODD Survey given to the DPR of women deceased from MBC, 3) a qualitative semi-structured telephone interview with DPRs after completion of the QODD survey, and 4) the mixed-methods study results focused on GOC discussions to a group of MBC multidisciplinary healthcare providers for stakeholder feedback and EOL care process suggestions.

Ultimately, by presenting this comprehensive, multifocal viewpoint of the EOL care of women deceased from MBC back to the HCPs with whom the treatment was conducted can allow for the development of targeted and meaningful approaches to EOL care for women currently diagnosed with MBC. The presentation for the study was focused on the following points:

- MM results #1: The perception of burden felt by experiencing any of the poor quality EOL indicators, according to the DPR.

- MM results #2: A profound sense of loyalty to the clinical staff, though not necessarily including the oncologist. Especially after the loss of their loved ones, the DPRs indicated that they felt quite lost both in relationship to the clinic staff and in routine.

- MM results #3: A limitation surrounding GOC discussions as noted by the DPR. While these conversations did occur for some, they were often cursory and late in the treatment course. The DPRs noted that a lack of prognostic awareness and

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meaningful content within GOC discussions led to lack of preparedness and planning for both their loved ones at the EOL and their experience after their loved one passed away.

8.3   METHODS

Study Design, Sample, and Setting

The design will be a qualitative content analysis of the stakeholder feedback after results are presented from studies 1,2, 3, and 4 according to specific, interviewed groups (i.e., RN staff members, licensed social workers, registered dieticians, direct-care advanced practice providers, palliative care team members, and MBC patient navigators).

The setting will be at a southwestern Pennsylvania cancer clinic of a National Cancer Institute (NCI) designated cancer center, as previously described for the initial MBC patient population.

The sample will include six different clinician groups within the southwestern Pennsylvania cancer clinic: 1) RN staff members, 2) licensed social workers, 3) registered dieticians, 4) direct-care APPs, 5) palliative care team members, 6) MBC patient navigators, and 7) MBC Tissue Procurement Specialist.

Focused presentation objectives included, 1) the perceived influence of experiencing any of the poor quality EOL care indicators for women with MBC, 2) clinic and staff loyalties, and 3) limitations surrounding GOC discussions.

Data Source/Data Collection

After the findings from studies 1, 2, 3, and 4 were integrated and best practice guidelines and implementation strategies coalesced, the PI attended an established meeting with all of the designated clinician groups. At the meeting, the PI presented a summary of the findings from studies 1, 2, 3, and 4 alongside the current practice guidelines. After the presentation was conducted, the PI then directed focused questions towards the clinicians regarding their opinion of the presented guidelines and implementation strategies, feasibility of practices, and actual integration within their current clinic practices. Additionally, the clinicians were able to provide their opinion regarding any facilitators or barriers to the provided suggestions of previous research. Meetings were conducted via Zoom due to Covid-19 precautions.

Analysis

From the stakeholder feedback group meeting, keywords, and themes around GOC discussions and EOL care wishes were identified according to the different clinicians and recorded in the respondent's own words. These themes were integrated and developed into best practice guidelines, modified for applicability within the MBC patient care context.

8.4   RESULTS

Following the presentation of the QODD surveys, qualitative interview content, MBC patient population chart review demographics, supportive care referral utilization, and poor quality EOL care indicators, the stakeholder meeting highlighted several themes that could be potentially influencing this process. Table 25 presents these themes in more detail with quote examples included.

Table 25: Barriers, Burdens, and Facilitators according to the Stakeholder Feedback Group

Barriers		Burdens		Facilitators	
Lack of information exchange	"…even when it's time, some of our oncologist push chemo and say, "I can fix you."" "Some people do wanna fight till the bitter end but maybe it's because they've never been shown another choice."	Insufficient time allowed	I think probably from what you're saying, more time needs to be allotted for everybody on a regular basis.	Equal timeline for GOC discussions regardless of subtype or prognosis	"I think that's why it's important to do it at the first metastatic visit. Because then everyone is treated equally. Like, we don't care if you progress or don't progress. You should understand that it's not a curable disease, I mean, even if you live with it for 25 years. If we talk to everybody at the first visit, will catch the people who don't do well and just have it in the back of their mind. It doesn't have to be like the big, you know, it can just be a casual thing."
Unknown optimal integration point of conversation	"And I mean, the one thing though, [MR], if you think about it personally – like you are very good at that. [A] was very good at that. [K] is very…like some people just are more comfortable with that and it shows through. So, I don't understand why it has to be like this, this line that we draw is just like, you know, can't one of the physicians say, "Oh [MR], it would be very helpful to me while you're here if you could talk to so and so for a minute." I mean, it's not a long term solution but I think it would get the docs thinking like, "ok, we should have this conversation, but I don't want to do it. Instead of like…" "But again, I think it's, I mean you've chosen something so dear to my heart, [RB], if you need help you call me because nobody wants to talk about this at all…ever."	Lack of specially trained staff personal	And I also think it might be a specific person or two because I personally have a very limited clinic experience, but I haven't met a single oncologist who's able to comfortably talk about end-of-life." "…that it's not done well, and it might better suit people to ummm, to – it might better suit the patients overall to have somebody who does these routinely and is very comfortable with them."	Standard "consent" for conversation	"You know, like consent, you can't start a new therapy without a consent. You should have a consent for, ummm, you know, if should be part of the…you know, they're not going to start a new treatment until, until they have a talk with somebody. You know, implemented into the protocol so that it isn't up to like, it's not up to the doctors whether or not a patients signs the consent for chemo…it's part of the rules. So that - I think it should be the same way."
Provider resistance	(see Unknown optimal integration point cell above)	Documentation inconsistencies	"It should be documented and the likelihood of the treatment working, umm, should be reiterated as well as the cost. You know, the actual side effects and the, the cost." "I think one of the big things is when you see…you don't see changes from note to note. You don't see like did they now say OK one more treatment like I don't see a unique patient profile in response to his…not in his in particular…but like any doctors really giving of that discussion, you know. I would have loved - and a few of them did something like, like, "patient is aware; now she now has another run, but she…she wait this long; once her child's school, you know." (*echoed in recording*) I don't know, I would have loved to see that this is their response. Those goals, all discussions and then someone else can follow it. As I was finding this patient was admitted to the inpatient Hospice or hospital, people would have no idea what that conversation actually was. Even if they had it, they couldn't follow it. Ummm, so, I think that's again documenting too is like, "how do we do this?" In a way that's doesn't	Realistic hope regarding prognosis	So, I think [MR]'s idea is just amazingly good that we could force them to at least acknowledge that you're burning through these chemos and, no matter what your oncologist says, your family should know at this point. I think that's the thing that really bothers me the most. Is these people that really do have such false hope that their families only know weeks before, when they've known for years, and I just find that I don't know if malpractice is the right word, but that's just heart wrenching to me to see these kids come in, "like do something!" And they have no idea we've done everything."

			"burden the staff who are already having a lot to do and then also being very thorough in capturing what this patient wishes to have happen."		
Current disease or treatment mentality	"I mean, that would be my, my hope and dream that that's you know, kind of the tone that that would be present: umm, is that, you know, you're not giving up if you stop, but, you know, it's you - don't have to continue getting treatment till the very end like, that's OK if you, if you decide that and we will support you." "One of the ancillary things you could do, would be to really kind of educate the staff - everyone on the staff - about this language of, ummm, fighting and you know all these war metaphors and, kind of, as best as like people just feel like, well I'm a loser cause I'm just giving up, I'm weak, I'm…you know." Instead, of like, "you are empowered to make whatever decision feels comfortable for you and your family. Just flip that switch and I think people wouldn't feel so intimidated and bullied into continuing these nonsense treatments."	Individual/hospital system bias	"But we have to be mindful of her own bias of what we think a good death is like. Like I had natural birth, but people who have epidurals - they can have an absolutely beautiful birth and have a wonderful memory. I would have felt like just I; I think I would have felt very sad about that, cause that wasn't my, my dream or my goal. But I, I cannot universally apply that to everyone, so there is something to be mindful about to not apply what we think is the, the, the, best death. I think it is encouraging, you know, practitioners to be able to have those conversations, so people do know their options…"	Provider/Oncologist support	"So, what I would love to see is, you know, an open, an open invitation to talking about this, as needed. Not every single appointment, obviously, but, but to set a tone of safety of you know that this is this is a disease that affects you mind, body and spirit, you know, holistically. That, you know, there's a lot that goes into having a metastatic diagnosis. And to sort of have that, umm, you know, I'm being very idealistic here in, in saying, you know, in saying that I hope this could be the approach, umm, with patients who have a terminal illness and to not have the onus solely be on the patient's shoulders to say, "I'm done" or you know, to bring that discussion up. It's very…it can be very intimidating, and it can feel like you're giving up on yourself, right? But if your physician is able to give you permission to say "hey, what do you want in your life?" This is, you know, and to not withhold information that could really affect what their last six months, or a year could really look like."
Provider and healthcare team emotional angst	"And whether it be just unique personalities that happen to, you know, be here right now, umm, It's hard to say but, but yeah, there definitely is, uhhh, you know, fear and trepidation around those conversations on our part."			Standard presentation of information for maximum disease and treatment awareness	"I don't think, though, that we're asking them to stop that hope. I think we're just asking them to let patients know about what if before we're at that road." "Yeah, but I think like when they tell you epidural or no epidural, they don't really make a preference for you. That's what I think we're missing. Is that telling people about end-of-life possibilities…it doesn't mean you have to pick one, we're just letting you know so that it will be in your mind. I think that's what we're lacking is like talking to people when they're healthy, so they understand what hospice is."
Cultural context	"I think generally is Americans, we struggle with death. We, we really as a culture don't approach it in the same way as some eastern cultures. Or you know, there's a lot of spirituality in other cultures that can help usher in death. Ummm, yeah, I mean, I think just our sort of curative perspective that we have that we want to eliminate." "So, I just think we've made it taboo somehow and it's just odd to me in an oncology				

	clinic that talking about the end-of-life is just not like a normal thing."
Disease context	"And there are things, umm, that are continuing to evolve, thankfully, ummm, but I've been told that as a result that a lot of patients, especially young women, who have breast cancer do have that sort of warrior mentality, and you know which has its positive attributes and aspects as well, but can make it maybe even more challenging to, to approach that conversation."

8.5 DISCUSSION

The barriers discussed by the stakeholder feedback group ranged from a lack of information exchange between the healthcare providers and the patient to noting the ever-changing cultural and disease contexts of MBC (Mack, Cronin, Taback, et al., 2012; Nedjat-Haiem et al., 2017; Piggott et al., 2019; Raskin et al., 2016). While each alone is noteworthy, these themes highlight the importance and intersection of the individual, hospital healthcare group, and disease community contexts contributing to the experience and quality of EOL care (Klawiter, 2004). Furthermore, whether locally, systemically, or nationally placed, the trickle-down effect of burdens within the healthcare system are producing fracture points around insufficient clinic time allowed per patient, the need for specially trained healthcare individuals, documentation inconsistencies, and EOL care biases. However, while these burdens are significant, according to the feedback stakeholder group, there is tremendous opportunity to improve the quality surrounding EOL care given current resources. Facilitators to this process can include interventions targeting the equal integration timeline for GOC discussions regardless of subtype or prognosis, standard presentation of information for maximum disease and treatment

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awareness, provider and/or oncologist support to meaningful GOC discussions, standardized "consent" for conversation with patients and their DPR about EOL care wishes, and maintenance of realistic hope in conjunction with prognosis.

8.6   CONCLUSION

8.6.1   Strengths and Limitations

There were several strengths to this study. First, the stakeholder feedback group was composed of several different disciplines and positions who interact daily in varying degrees with women diagnosed with MBC. This makes them uniquely qualified to provide feedback in response to the presented information. Secondly, the stakeholder feedback group was obtained through the primary setting of the study and therefore, could speak in specificity to the data collected and subsequently presented. We would also acknowledge, however, that it was a smaller group of healthcare providers giving feedback as well as a single location. This may limit generalizability of the recommendations for other MBC clinics and healthcare teams and would need to be reexamined in other locations and contexts.

9.0   FUTURE DIRECTION AND CONCLUSION

9.1   FUTURE DIRECTION

This dissertation study has implications for future research. The findings from the retrospective chart review, QODD survey, qualitative interview, mixed methods analysis, and the stakeholder feedback focus group, suggest a significant need for translating this information into a usable action plan for current MBC clinicians. Prospective identification of women diagnosed with MBC, using the suggested demographic, social, patient health, and clinical factors will potentially alleviate undue disease and treatment related burdens at the EOL. Furthermore, a protocolized approach to integrating meaningful and timely GOC discussions into the standard of advanced cancer treatment according to the individualized needs of the patient would in turn allow for the proper integration of healthcare and social services, including palliative care, based on the individual and family care needs.

Taking this holistic approach of identifying not only the physical needs and symptom burdens, but social, spiritual, and emotional needs as well will promote individualized goal concordance and high quality EOL care. Future studies will require the testing of suggested factors into the current MBC patient population as well as integration within other health care systems as well. This will not only allow for confirmation of this study's results but could

strengthen the utilization of these factors across a number of healthcare systems and advanced cancer or life-limiting illnesses.

9.2   CONCLUSION

This dissertation study emphasizes the importance of capturing the intersection between demographic, social, patient health, clinical, and. support care factors, advance care planning, and goals of care with the quality of EOL care perceived to have been received according to the DPR. While both women diagnosed with MBC and their DPR each experience a unique understanding of what it means to have a MBC diagnosis, there must also be an awareness of the influence from shifting treatment paradigms, medical developments, cultural contexts, and disease specific burdens. Each of these components are vital to understanding what truly dictates the quality of EOL care. Furthermore, while it is important to have measurable outcomes, as we have seen from the inclusion of poor quality EOL care indicators and standards of EOL care, we must be mindful of fluctuating and dynamic individual and family wishes. If we do not, the risk of measuring what is not meaningful to the patient remains ever-present and, therefore, ever-burdensome.

APPENDIX A - Dissertation Study Institutional Review Board Approval

University of Pittsburgh | Institutional Review Board
Office of Research Protections

APPROVAL OF SUBMISSION (Expedited)

Date:	September 7, 2020
IRB:	STUDY19020029
PI:	Rachel Brazee
Title:	Quality of End of Life Care (EOL) with Metastatic Breast Cancer (MBC)
Funding:	None

The Institutional Review Board reviewed and approved the above referenced study. The study may begin as outlined in the University of Pittsburgh approved application and documents.

Approval Documentation

Review type:	Initial Study
Approval Date:	9/7/2020
Expiration Date:	9/6/2021
Expedited Category	(6) Voice, video, digital, or image recordings, (7)(b) Social science methods

Determinations:	• Waiver of consent documentation
Approved Documents:	• QODD questionnaire, Category: Data Collection; • Telephone Interview Questions, Category: Data Collection; • Telephone Interview Verbal Consent Form, Category: Waiver Script; • Qualtrics Survey Consent Form, Category: Waiver Script; • Bibliography, Category: Other; • CORID Approval Letter, Category: Data Collection; • Recruitment Email, Category: Recruitment Materials;

As the Principal Investigator, you are responsible for the conduct of the research and to ensure accurate documentation, protocol compliance, reporting of possibly study-related adverse events and unanticipated problems involving risk to participants or others. The HRPO Reportable Events policy, Chapter 17, is available at http://www.hrpo.pitt.edu/.

Continuing review (CR) can be submitted by clicking "Create Modification/CR" from the active study at least 5 weeks prior to the expiration date.

Clinical research being conducted in an UPMC facility cannot begin until fiscal approval is received from the UPMC Office of Sponsored Programs and Research Support (OSPARS).

If you have any questions, please contact the University of Pittsburgh IRB Coordinator, Teresa McKaveney.

Please take a moment to complete our Satisfaction Survey as we appreciate your feedback.

APPENDIX B - Dissertation Study CORID Approval

University of Pittsburgh

Committee for Oversight of Research and
Clinical Training Involving Decedents

Office for Oversight of Anatomic
Specimens
Iroquois Building, Suite 302
3600 Meyran Avenue
Pittsburgh, PA 15261
412-802-8280, Fax: 412-647-1920
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MEMORANDUM

TO: Rachel Heckmann, MD

FROM: Barbara E. Barnes, MD
            CORID Chair

DATE: May 18, 2021

RE: CORID No. 1052: Quality of Death (QOD) for patients diagnosed with Metastatic Breast
Cancer (MBC)

The Committee for Oversight of Research and Clinical Training Involving Decedents has
reviewed and approved the Annual Renewal Report for the above-referenced study.
The next report will be due on or before the date indicated below. When your study has been
completed, a Final Report will be required.

> **Approval Date: 05/18/2021**
> **Renewal Date: 05/17/2022**

Should you have any questions, please contact Krystal Golacinski, CORID Administrator, at 412-
647-7050, or via email at moorekL2@upmc.edu.

Thank you.

c: Monica Linde

University of Pittsburgh

Committee for Oversight of Research and
Clinical Training Involving Decedents

MEMORANDUM

TO: Rachel Heckmann, MD

FROM: Barbara E. Barnes, MD
            CORID Chair

DATE: June 12, 2020

RE: CORID No. 1052: *Quality of Death (QOD) for patients diagnosed with
Metastatic Breast Cancer (MBC)*

The Committee for Oversight of Research and Clinical Training Involving Decedents has
reviewed and approved the above-referenced study.
A renewal report is required annually, with the first due on or before the date indicated below.
When your study has been completed, a Final Report will be required.

Approval Date: 06/12/2020
Renewal Date: 06/11/2021

Should you have any questions, please contact Krystal Golacinski, CORID Administrator, at
412-647-7050, or via email at moorekL2@upmc.edu.

Thank you.

c: Monica Linde

APPENDIX C - Optional Telephone Qualitative Interview Guide

Domain of Interest	Subset of Domain of Interest	Sample Question
Experiences surrounding care		
	Pre-diagnosis	Can you tell me about your loved one having any past experiences with other family members or friends that had a similar medical condition (serious illness, condition, hospitalizations, etc.)? How did you feel this affected you? - How did this affect you and your wife approach?
	Diagnosis (knowledge of)	Can you tell me about the day that Dr._____ spoke to you about the cancer diagnosis and what to expect? Can you tell me about the experience? How do you think your wife felt about it? How was that information delivered to you and your loved one? Can you describe how often and the ways in which new information or education was provided to you and your loved one about the disease diagnosis and progression? *Prompt: How did you accomplish this?*
	Progression of disease	How did your loved one's diagnosis and disease progression effect day to day activities, planning, and priorities? Can you talk about you and your loved ones' preferences and expressed needs and if they were met throughout her diagnosis and treatment? *Prompt: Were you and your loved one able to participate in gatherings with friends or family?*
Support		
	Emotional	Can you share ways in which you felt supported…by family…by the clinical team? Can you verbalize any hopes and expectations that you or your loved one had which may or may not have been met?
	Physical	Can you discuss how your loved one's physical limitations were acknowledged and met by the clinical staff?
	Psychosocial	Did you or your loved one experience any financial needs or hardships? Did you feel like that affected the care you received? Were these acknowledged by the clinical staff? *Prompt: For example, this could include parking costs, childcare needs, etc.*
	Spiritual	Tell me about any spiritual or religious beliefs, did this help to guide you or your loved one at any point after diagnosis and throughout treatment?
End of Life		
	Goals of care	Some of our patients feel that they are unsure about the end of their life and what they would want that experience to look like. Do you know if your loved one experienced those same concerns? How did you navigate end-of-life conversations? Do you remember a point in conversations, where they talked about any changes in the outcomes/outlook? Was there a time where there was a definite shift in goals of care or prognosis? Did they ever offer you a

		choice of options, what is really based in shared-decision making process? Align the treatment with your goals? Did they at any point, did they ask what your goals were, or what would be important to you if treatments continued to be unsuccessful or if treatment were burdensome.
		Did anyone ever talk to you about what was important to help you decide what treatment to choose? That the condition was getting serious.
		Did you have a goals of care meeting to discuss this in detail? If so, who was the meeting conducted with? Was it over a period of time?
		Would you have wanted to know earlier? If you had known that information, what would you have done differently?
		Prompt: This could be a discussion about advance care planning, code status, life goals, etc.
	End of Life Poor Quality Indicators	Some of our patients have different end-of-life care needs and wishes.
		Did your loved one experience any chemotherapy in the last month? no
		If yes, was it a new chemotherapy or continuation of treatment?
		Do you know if this was what she had wanted?
		Did your loved one have to seek treatment more than once in the emergency department in the last month?
		For some patients, this can provide a sense of comfort that they are still be treated, for others it becomes too invasive. Do you know if this was what she had wanted?
		Was your loved one admitted more than once to the hospital in the last month of life?
		With those admissions, did she require at any time a visit to the intensive care unit?
		Can you tell me about hospice services? Was your loved one given information about those services or offered a referral?
		If yes, how long was your loved one in hospice?
		Can you tell me about where your loved one passed away? home
		Was she able to verbalize where she had wanted to be when she passed away? yes
	Patient-specific	Can you tell me if there were any specific goals that your loved one wished to do or see before their passing?
		Can you describe anything that you or your loved one experienced that was perceived as high quality or poor quality end-of-life care?
Quality of Death		
	Dying process	What things did you appreciate about the way in which your loved one passed?
		What things did you find increased the difficulty of your loved one passing?
		Prompt: how was it interacting and communicating with your healthcare team or family members.
Aftercare		
	Bereavement	Looking back, how can we best support you in your grieving process?

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