FACTORS AFFECTING PAIN MANAGEMENT SELF-ADVOCACY IN WOMEN AGED 65 AND OLDER WITH BREAST CANCER

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University of Pittsburgh, 2022

Background: Despite advancements in treating cancer and cancer-related pain, patients with breast cancer continue to self-report high percentages of pain. Because women aged 65 and older comprise the highest percentage of breast cancer survivors, much attention is due to this group to determine the extent and the cause of undermanaged pain. Therefore, the purpose of this study was to understand factors that affect pain management and pain self-advocacy experiences of in this group of women treated for breast cancer.

Methods: Females aged 65 and older were recruited from a larger ongoing longitudinal study. For the first aim, we employed qualitative descriptive methodology to interviews with 21 study participants, aged 65 or older, who endorsed pain scores of 4/10 or higher at least once during parent study participation. Questions focused on interactions with the cancer care team, experiences and practices of reporting and treating their pain, and opinions regarding pain management with opioid analgesia. For Aim 2, 73 parent study participants aged 65 or older were recruited to participate in a single questionnaire comprised of items from four instruments: the Female Self-Advocacy in Cancer Survivorship scale; the Patient-Centered Communication in Cancer Care (short-form) instrument; the Brief Opioid Stigma Scale; and the Patient-Reported Outcomes Measurement Information System (PROMIS®) Scale v2.0 - Pain Intensity 3a.

Results: The findings from Aim 1 revealed three overarching categories: facilitators of optimal pain management, challenges to optimal pain management, and other factors affecting

optimal pain management. The results of Aim 2 revealed negative correlations between scores of pain intensity and perception of patient-centered communication and with opioid stigma agreement. Positive correlations were found between scores for perception of patient-centered communication and overall self-advocacy, particularly with the informed decision-making, effective communication, and connected strength subscales.

Conclusions: Strategies that employ facilitators of optimal pain management can mitigate barriers that may affect how pain is managed in women aged 65 and older who are breast cancer survivors. Future research should focus on improving patient-centered clinical relationships and increasing self-advocacy skills to promote optimal pain management in this population.

Table of Contents

List of Tables

List of Figures

Preface

To the amazing women from the University of Pittsburgh Medical Center (UPMC) Hillman Cancer Center Comprehensive Breast Program who willingly participated out of their desire to make life better for patients with cancer, I give my utmost thanks and highest praise. Without wonderful participants who are willing to share their stories with others, none of this research would have been possible. It is my sincerest hope that this dissertation study and all the work that follows will be reflective of their experiences and contribute to improving the lives of all patients with cancer.

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Obtaining a PhD in Nursing could not have been achieved without God's divine power and the unwavering love and support of my family and friends—I thank you all. To my brilliant and wonderful husband Barm, I can never thank you enough for always believing in me and supporting me beyond what I could have possibly imagined.

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1.0 Introduction

From onset through survivorship, pain is one of the most frequently reported symptoms associated with cancer (Miller et al., 2019), and more than a third of patients classify their cancer pain as moderate to severe (Wordliczek et al., 2018). The problem of suboptimal pain management in patients with cancer existed well before the escalation of the current opioid crisis. Misperceptions of pain relief modalities; lack of patient-centered communication between patients and healthcare providers; and fear of adverse effects associated with opioids such as severe nausea and vomiting led to underreporting and subsequent undertreatment of pain (Bouri et al., 2018; Donovan et al., 2007; Ruben et al., 2018). Worldwide, unmanaged pain is significantly burdensome from a public health care and socioeconomic perspective (Goucke & Chaudakshetrin, 2018) and is particularly impactful throughout the cancer care continuum. Acute pain signals oncologic emergencies, including spinal cord compression and increased intercranial pressure, necessitating urgent diagnosis and treatment (Alsharawneh & Hasan, 2021). Far-reaching and long-term consequences of continued undermanagement of pain include increased healthcare costs due to increased debility and loss of function; delayed treatment of illness resulting in disease progression; and decreased quality of life for patients and their caregivers due to its negative impacts on physiological and psychological functioning (Brant, 2018; Cope, 2019).

Increased attention to the opioid crisis in the United States and associated beliefs regarding adverse effects of opioid analgesia restricts the ability of patients with cancer to adequately manage their pain (Kwekkeboom et al., 2021; Martinez Tyson et al., 2021). Opioids continue to be the optimal treatment modality for moderate to severe cancer-related pain (Wright et al., 2019). However, repercussions from the opioid crisis have stigmatized opioid use, resulting in

increased patient and provider hesitancy in requesting and prescribing opioids, respectively (Page & Blanchard, 2019). These consequences exacerbate opioid stigma, which manifests itself as maladaptive behaviors influenced by fear of adverse effects such as addiction and sedation as well as experienced and/or anticipated judgment from others regarding their choice to employ opioid analgesia (Bulls et al., 2022). The negative impacts of these consequences contribute to the problem of inadequate pain management by impairing direct communication regarding pain status and management between patients with cancer and their healthcare providers (Bulls et al., 2022).

Women with breast cancer aged 65 and older are one of the world's largest groups of patients with cancer (Roberts et al., 2020) and comprise the largest segment of breast cancer survivors (Mandelblatt et al., 2020). In the United States, approximately 407 in every 100,000 women aged 65 years or older are diagnosed with breast cancer each year, with prevalence peaking between the ages of 70–74 (U.S. Cancer Statistics Working Group, 2021). As the incidence of breast cancer continues to rise in this population, long-term risks of cancer recurrence also persist as they age (Angarita et al., 2018). As of 2030, the Baby Boom generation will all have reached age 65 with a projected total of 73.1 million, comprising 21% of the population (Vespa et al., 2020). By 2040, the number of cancer survivors is predicted to reach approximately 26 million, of which 73% will be aged 65 years and older and almost 50% of those over 75 (Sedrak et al., 2021). The increased number of individuals aged 65 and older with cancer also leads to an increase in healthcare burden and costs to individuals, caregivers, health systems, and society as a whole (Al-Qurain et al., 2020).

Advanced age presents a barrier to the achievement of adequate pain management for patients with cancer. Altered pharmacokinetics, pharmacodynamics, pain tolerance, and pain

thresholds in adults aged 65 and older complicate dose titration in opioids (Hachem et al., 2019) and further complicate pain management. Al-Qurain et al. (2020) attributed polypharmacy, multiple comorbidities, and altered physiology as factors that increase the vulnerability of adults aged 65 and older to adverse effects of analgesics. From a quality of life perspective, pain is a common cause of symptom distress and functional impairment in adults aged 65 and older, requiring judicious drug selection to ensure safe therapy given the varied adverse-effect profiles of analgesics and potential interactions with multiple other medications (Portenoy, 2020).

Adults with cancer who are aged 65 and older often adopt a passive approach when communicating new onset acute pain or undermanaged chronic pain to healthcare providers (Brunello et al., 2019), presenting another challenge for their adequate pain management. This passive behavior can result from fears of adverse effects from opioid analgesia such as addiction and death from overdose (Graczyk et al., 2018) and their tendency to accept pain as an unavoidable pitfall of aging, especially adults aged 65 and older belonging to racial and ethnic minority groups (Bierman et al., 2018, Robinson-Lane et al., 2022). Reluctance of adults with cancer who are aged 65 or older to discuss pain with their healthcare providers is associated with multiple factors including female gender, advanced cancer stage, location of primary cancer site, poorer performance status, and higher number of comorbidities (Brunello et al., 2019).

To identify where, along the trajectory of treatment of early-stage breast cancer, the experience of unmanaged and undermanaged pain is most problematic among women aged 65 and older, we conducted a pilot study (Alsbrook et al., 2021) of the pain experiences of a cohort of women aged 65 and older (n = 57). The pilot study was a secondary analysis of women who were participants in the “Genomic Underpinnings for Breast Cancer Treatment-Induced Nausea and Vomiting” study (NR016695, Susan Wesmiller, PI). We analyzed perioperative and symp-

tom data collected during the immediate postoperative period and at 48 hours post-discharge. Variables in the pilot study included numerical rating scale (NRS) pain scores; surgical procedures and types of anesthesia; and dosage, frequency, and types of opioid analgesia administered. A linear regression model of these factors revealed an association between the type of opioids received and the dosage of opioid analgesia required. Findings from the pilot study reflected that pain was well-managed during the postoperative period; more than 50% of study participants did not require pain management with opioids post-discharge; and the majority of those who required opioid analgesia self-administered only one or two doses (Alsbrook et al., 2021). We concluded from these data that well-managed postoperative pain extended to the 48-hour period post-discharge for the majority of study participants. However, two participants who reported high pain scores (7 out of 10 and 10 out of 10, respectively) 48 hours after discharge both reported self-administering only one prescribed opioid tablet despite describing themselves as "in a lot of pain" and "achy, painful" at this timepoint (Alsbrook et al., 2021).

The reasons behind participants' decision not to effectively employ the analgesics prescribed to them for managing their pain post-discharge motivated further exploration of the factors associated with the decision among adults aged 65 and older to undermanage their pain. Factors may include those reported in a previous qualitative study of adults aged 65 and older who experienced persistent pain over a three-month period (Makris et al., 2015) in which interviews and focus groups revealed that negative attitudes toward medications and negative patient-provider interactions, such as lack of collaboration with the patient in treatment planning, deterred study participants from reaching out to their providers to discuss analgesic options. Furthermore, pain in adults aged 65 and older tends to be inadequately evaluated and consequentially undermanaged, particularly those with cognitive deficits (Hachem et al., 2019) who, when un-

able to verbalize their pain, may exhibit other signs of pain including agitation and changes in behavior, mood, functionality, sleeping and eating habits (Cope, 2019). These factors have an additive effect to the other multiple roadblocks patients with cancer encounter when seeking adequate pain management. Table 1 lists patient, provider, and systemic barriers to adequate pain management reflected in the current literature.

Brunello et al. (2019) recommend multidisciplinary approaches to comprehensively address barriers to adequate pain management. One approach involves equipping women with self-advocacy skills to proactively collaborate and communicate with their cancer care teams regarding management of cancer-related symptoms, including pain, early in their breast cancer treatment trajectories (Thomas et al., 2019). Self-advocacy for adequate pain management in the context of cancer survivorship involves making informed decisions; communicating effectively with one's healthcare team; and connecting to others through shared support and strength (Thomas et al., 2020). Ideally, oncologic providers and patients with cancer collaboratively determine and manage all aspects of cancer care, including cancer-related pain management; however, adults aged 65 and older and patients with less education, income, and resilience typically prefer a more passive role in the decision-making process (Colley et al., 2017). Little is known about how women aged 65 and older with breast cancer self-advocate for better pain management and the factors that influence communication with their cancer care teams about pain management. Thus, the tendency of women aged 65 and older not to self-advocate for their needs may be an important impediment to achieving adequate pain management.

Table 1. Barriers to adequate pain management

Author/Year	Identified Barrier	Type of Barrier		
		Patient	Provider	Systemic
Goucke & Chaudakshetrin, 2018	-Education of medical, nursing, and allied health graduates and established healthcare providers		X	X
Hachem et al., 2019	-Inadequate evaluation/assessment		X	
Kolmes et al., 2020	-Lack of standardized pain treatment between genders			X
	-Inequality among recommendations for pain intervention		X	
Kwekkeboom et al., 2021	-Fear of opioids' harmful effects (e.g., addiction)	X		
	-Fear of side effects of opioid analgesia	X		
	-Belief that it is impossible to manage their pain	X		
	-Reluctance to reach out careteam regarding pain	X		
	-Public health messages regarding opioid misuse increased fear to utilize opioid analgesia for pain management			X
Kwon, 2014	-Nonadherence to recommended analgesic regimens	X		
	-Quantity limits on opioids			X
	-Lack of access to pain and palliative care professionals			X
Luckett et al., 2019	-Lack of goal-setting/optimal pain self-management	X		
	-Lack of a set plan for pain management and who to contact for new onset acute pain and/or undermanaged chronic pain		X	
	-Lack of sufficient pain screening and pain care coordination		X	X
	-Poor prioritization of pain management and communication		X	
Martinez-Tyson et al., 2021	-Fear of addiction	X		
	-Lack of non-opioid interventions for unmanaged pain			X
	-Failure to identify/treat opioid use disorder		X	
	-Policies aimed at opioid epidemic restrict opioid access for patients with cancer			X
Meghani et al., 2020	-Incorrect usage of opioid analgesics (e.g., tapering self off opioids, using long-acting opioids as needed rather than taking as prescribed/scheduled; mixing opioids with over-the-counter analgesics)	X		
	-Insufficient insurance coverage leading to high co-pays that deter adherence to analgesic regimen			X
	-Individual pain self-management practices/beliefs	X		
Paice, 2018	-Reluctance to communicate new onset pain to provider	X		
	-Assumption that careteam is aware of undermanaged pain	X		
	-Insufficient training for adequate pain assessment		X	
	-Reluctance to prescribe opioid analgesia		X	
	-Limited access to pain care (e.g., pain clinics)			X
	-Limits on insurance coverage of pain management modalities			X
	-Opioid supply shortages in hospital and retail pharmacies			X
Reville & Foxwell, 2014	-Lack of integration of palliative care with cancer care		X	X
	-Need for public awareness and education regarding appropriate dosing, safe handling of opioid analgesia	X		X
Wright et al., 2019	-Nonadherence due to disruptions in sleep-wake cycle and cognitive side effects from opioid analgesia	X		
	-Delays/difficulties in obtaining opioid analgesia		X	X
	-False beliefs regarding opioid analgesia (e.g., taking the minimum dose needed to manage pain prevents addiction)	X		

The purpose of this study was to better understand the factors that affect the pain management and pain self-advocacy experiences of women aged 65 and older who received treatment for breast cancer. For Aim 1, a qualitative inquiry of participants' experiences with pain management was conducted. Aim 2 describes associations among overall and component scores of self-advocacy and pain intensity, patient-centered communication, opioid stigma, and individual precursors in a cohort of women aged 65 and older from a one-year longitudinal study following surgery for breast cancer (see Figure 1).

1.1 Aims

Aim 1: Explore the experiences and factors influencing pain management among women aged 65 and older who reported moderate to severe pain within the first year after breast cancer surgery. Qualitative findings from one-on-one, semi-structured interviews underwent qualitative analyses for codes and themes reflective of the lived experiences of women aged 65 or older treated for breast cancer (N=21) who reported a pain level of "4" or greater on the 11-point Numerical Rating Scale (NRS) during the first year of parent study participation.

Aim 2: Describe the associations among self-reported scores for: 1) levels of self-advocacy; 2) patient-centeredness of communications with healthcare providers; 3) stigma regarding opioid use and addiction; and 4) ratings of pain intensity among a cohort of women with breast cancer aged 65 and older. We prospectively enrolled participants aged 65 or older (N=73) from a cohort of women with early-stage breast cancer who participated in the parent study for at least one year. We obtained these data from participants' responses to survey questions during both parent study and present study participation. This aim is illustrated in Figure 1 below:

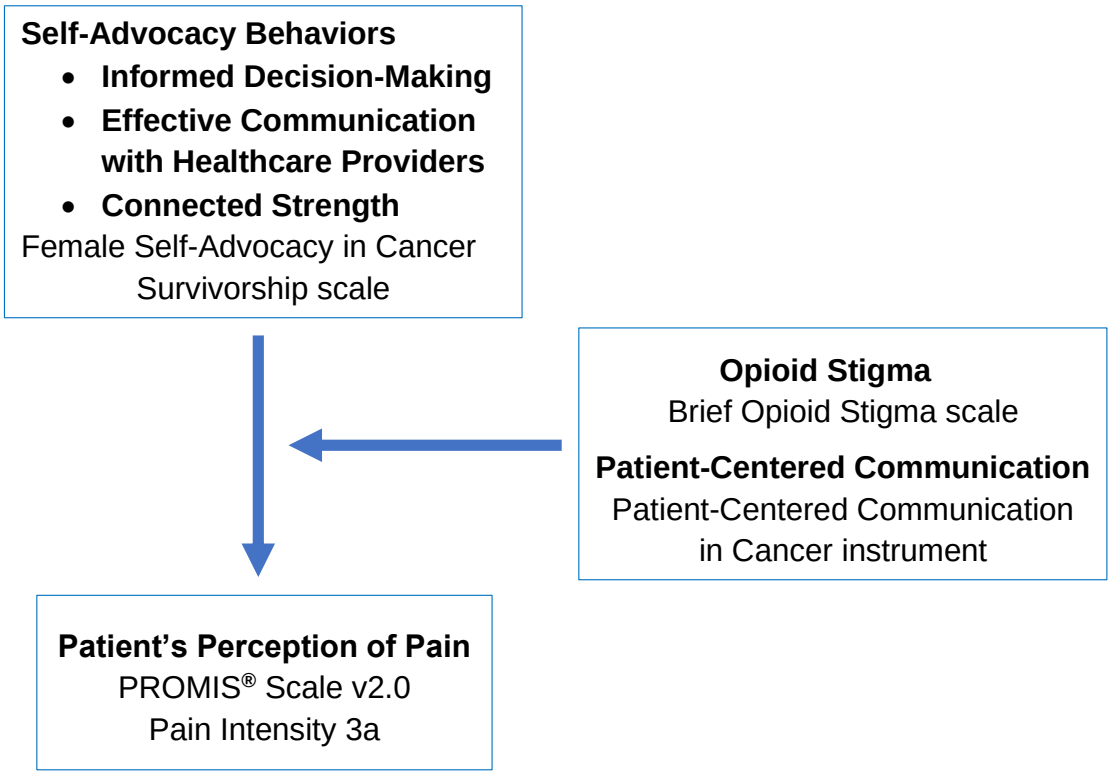

Figure 1. Adapted model of pain management self-advocacy for women aged 65 and older with cancer

1.2 Background and Significance

1.2.1 Undermanaged pain

Inadequate pain management for patients with cancer remains a major public health concern. Cancer pain is difficult to treat due to the complex pathological processes at the root of its cause, including proliferating tumor tissue; multiple mechanisms such as inflammation, neuropathy, and ischemia; and adverse effects of anticancer treatment and unrelated concomitant disorders (Wordliczek et al., 2018). Despite improved clinical practices, mandates from agencies that

govern patient care practices, and advancements in pharmaceutical development over the years, unacceptably high percentages of patients with cancer continue to report undermanaged pain (Kwekkeboom et al., 2021; Wordliczek et al., 2018). A study by Kwekkeboom et al. (2021) concluded that 40% of study participants with pain resulting from advanced or metastatic cancer failed to self-administer sufficient dosages of analgesics to palliate their pain adequately. Another major study by Wordliczek et al. (2018) revealed cancer pain prevalence as high as 39% following treatment completion; 55% during active anticancer treatment; and 66% in its advanced stages with 38% overall classifying the pain as moderate to severe.

The opioid crisis is occurring simultaneously with the ongoing need for patients with cancer to access strong opioids essential to management of their pain, despite the side effects some patients experience (Bennett, 2017; Hertz & Throckmorton, 2019). Since 2011, the peak timepoint of the opioid crisis (Preuss et al., 2019), regulatory pressure and opioid prescription guidelines have successfully decreased the number of opioid prescriptions and the amounts administered. Unfortunately, these approaches emphasized opioids as the primary problem rather than addressing the driving forces behind their misuse (Gallagher, 2018), creating a crisis of access for patients in need of effective therapies for treatment of pain (Hertz & Throckmorton, 2019). Oncologists and oncology advanced practice providers (APPs) continue to be the primary managers of pain for patients with cancer (Page & Blanchard, 2019). However, consequences of the opioid crisis such as the fear of legal action on prescribing habits; the lack of knowledge regarding appropriate pain assessment and analgesia coverage; and the necessity to negotiate barriers to opioid prescriptions further contribute to prescribers' tendency to arbitrarily restrict opioid analgesia dosages, resulting in undertreated cancer-related pain (Page & Blanchard, 2019; Paice, 2018). Despite these roadblocks to adequate pain management, the basis of the dissertation study

is that the lack of self-advocacy skills pertinent to adequate pain management such as effective communication with the cancer care team (Thomas et al., 2020) may be the root cause of many instances of undermanaged pain, as pain interventions cannot be enacted unless the care team is notified of the need for action.

1.2.2 Opioid stigma

The National Cancer Institute (2019) reports that the increased prevalence of cancer pain and the impact of the opioid epidemic on cancer pain management necessitate the development of new approaches to pain management. One such approach is through application of the framework of opioid stigma, as developed by Bulls et al. (2022). Opioid stigma, also known as "opiophobia" in earlier literature, may manifest itself as internalized fears regarding one's own prescription opioid use, perpetuated by perceived judgments from others and/or experiences of discrimination (Bulls et al., 2022). Opioid stigma contributes to inadequate cancer pain management by impairing forthright and adequate communication between patients and their care teams regarding pain status and management planning (Graczyk et al., 2018).

The ongoing opioid crisis has led to pervasive opioid stigma and reinforcement of existing hesitancies to discuss and self-administer opioids among patients with cancer (Bulls et al., 2019; Page & Blanchard, 2019). Fear of addiction; intolerance of side effects; building up tolerance to analgesia; lack of training on employing analgesics appropriately; and impaired cognition are also common definitive themes of opioid stigma that contribute to patients' underreporting and subsequent undermanagement of their pain (Cella et al., 2016; Paice, 2018). Barriers to achieving optimal pain management perpetuated by opioid stigma include limitation of patients'

engagement in their care; impediment of health-promoting behaviors; reduction of available resources; decreases in social support; and exacerbation of emotional distress (Bulls et al., 2022).

1.2.3 Patient-centered communication

Patients with cancer often hesitate to self-report changes in their pain management status to their caregivers or healthcare teams because they feel they would be viewed as being a nuisance to their providers, the consequences of which are undertreatment of their increasing pain and impaired functionality (Bouri et al., 2018; Paice, 2018; Ruben et al., 2018). Lack of and/or ineffective communication between patients and healthcare providers is detrimental to the assessment and management of pain in adults aged 65 and older. Suboptimal communication is associated with decreased self-reporting of pain symptoms, leading to increased pain intensity and impaired functionality (Bouri et al., 2018; Ruben et al., 2018). Both patient and provider factors contribute to poor communication about pain. Patients with sensory deficits such as hearing loss may find it difficult to understand questions related to pain assessment, and those with cognitive impairments including dementia and other age-related brain disorders may not be able to express or report pain (Brant, 2018). Minaya-Freire et al. (2020) attributed other patient factors to inadequate pain management, including agitation, restlessness, depression, multiple pathologies requiring multiple medications leading to drug interactions, and reluctance to comply with medication regimens. Provider factors include analgesia dosing decision-making based on limited knowledge of analgesic delivery modalities and their side effects; inadequately dosing and prescribing opioids; failing to implement pain guidelines and set clear pain management standards; and lacking understanding of patients' expectations of achieving pain goals (Bouri et al., 2018). Fortunately, improvements in the area of palliative care have improved pain outcomes for

adults with cancer who are aged 65 and older (Shachar et al., 2016). However, research findings persistently indicate that patients, providers, and caregivers continue to misconstrue that a recommendation to receive palliative care equates with end of life care (Cardenas et al., 2021) causing hesitation to collaborate with palliative care for pain management. Additionally, adults with cancer aged 65 and older are less willing to address issues involving pain, as they tend to view pain as an expected consequence of cancer to which they must adapt (Dunham et al., 2017).

In their study of 1,027 patients' perceptions of patient-centered care, Ruben et al. (2018) found that provider communication was significantly negatively related to pain intensity and pain interference. They concluded that providers may be able to elicit higher levels of self-efficacy in their patients by providing patient-centered communication, which would reduce the intensity of pain and level of pain interference in their patients' lives (Ruben et al., 2018).

Few researchers have examined the relationship between perceptions of communication and health outcomes or the mechanisms by which communication may improve patients' individualized pain experiences (Ruben et al., 2018). This gap flags an ongoing need for improvement in the patient-provider communication dynamic. Poor communication of unmitigated symptoms experienced by patients continues to be problematic despite the call by Donovan et al. (2005) for needed research in the area of patient-centered communication. Evidence as to whether patient-centered communication improves outcome measures such as decreased symptom severity; improved overall quality of life; and reduced morbidity and mortality for patients with cancer is still needed. Fostering a patient-centered relationship focused on shared decision-making between adults aged 65 and older and their care teams leads to optimal patient outcomes including continuity of care; facilitation of communication regarding patient goals and preferences; and a more targeted focus on the needs of the patient and caregiver (Bunn et al., 2018).

1.2.4 Female Self-Advocacy in Cancer Survivorship

The Female Self-Advocacy in Cancer Survivorship (FSACS) framework is the central theoretical model for this study. This conceptual framework provides an empirical and conceptual guideline for research aimed at understanding and improving self-advocacy among women with cancer based on three main constructs: informed decision-making; effective communication with healthcare providers; and connected strength (Thomas et al., 2020). While similar concepts focus on patients' ability to self-manage their illness, self-advocacy focuses on equipping patients with the skills necessary to overcome challenges they meet along the trajectories of their personal cancer journeys to optimize their cancer care so that it fundamentally addresses their needs, values, and priorities (Hagan et al., 2018a). Self-advocacy involves identification and definition of personal preferences; discernment between risks versus benefits of both cancer treatment and management of the adverse effects of treatment and the cancer itself based on personal priorities; and cultivating a relationship with the cancer care team in which the patient has an active voice in ensuring that the plan of care aligns with their preferences (Hagan & Donovan, 2013a). In contrast, the inability of a patient with cancer to self-advocate is evidenced by lack of internal and/or external support systems; behaviors that do not reflect the ability to seek information or solve problems; and no demonstrated ability to navigate the healthcare system, make informed decisions, or foster a spirit of collaboration with the cancer care team (Hagan & Donovan, 2013b).

1.2.4.1 Informed decision-making

Informed decision-making involves behaviors such as accessing health information; recognizing timepoints in the cancer treatment trajectory for which it will be necessary to make de-

finitive decisions; weighing available options and identifying the risks and benefits of each; and basing these decisions on personal needs and priorities (Thomas et al., 2020). However, this is a skill that requires cultivation over time, especially learning to separate reliable, well-researched information from widely-available misinformation. Other challenges to making informed decisions include getting personally-relevant information; communicating more effectively; finding and addressing health information; and feeling overwhelmed by medical information (Hagan et al., 2017). However, multiple studies have proven that informed, shared decision-making between patients and their providers improves quality of care and leads to high quality communication between patients and care teams within cancer contexts (Heathcote et al., 2018).

1.2.4.2 Effective communication

The hallmark behaviors of effective communication with healthcare providers include asking questions; conveying personal preferences and opinions; sharing personal experiences; and communicating concerns in an open, non-adversarial manner (Alpert et al., 2019; Thomas et al., 2020). Patients' ability to effectively communicate their needs to their care team results in higher satisfaction with care; greater adherence to treatment; reduced anxiety; and increased knowledge and improved understanding for cancer survivors (Radziej et al., 2017). In their discussion of the American Society of Clinical Oncology (ASCO) consensus guideline for Patient-Clinician Communication, Gilligan et al. (2018) emphasized the importance of optimal communication and its significance in the formation of a positive patient-provider relationship containing the elements of mutual respect, trust, and empathy. This positive relationship facilitates discussions that may otherwise be difficult, such as conversations regarding goals of care and prognosis; treatment options and clinical trial participation; and end-of-life care (Gilligan et al., 2018). Cultivating the skill of effective communication with healthcare providers is particularly

vital to patients with cancer, as movement along the cancer continuum increases the complexity of medical issues and the tendency to require multiple specialists who seldom communicate with one another, requiring patients' wherewithal to follow up on unresolved problems (Ramshaw, 2020) such as unmanaged or undermanaged pain. Luckett et al. (2019) identified lack of coordinated care as the most important barrier to timely, high-quality pain management and access to analgesia. This finding further punctuates the importance of effective communication in optimal pain management.

1.2.4.3 Connected strength

Connected strength is embodied in how individuals self-advocate by gaining strength through connection to others, and its key behaviors include soliciting support from others; providing support to others; sharing cancer experiences with others; and raising awareness regarding cancer (Thomas et al., 2020). A recent study of 200 patients with cancer (Ruiz-Rodríguez et al., 2021) demonstrated that satisfaction with the support provided to them related more significantly to quality of life than did the frequency with which that support was provided. Furthermore, emotional support from family supplemented by informational support from friends decreased patients' perceived stress and increased quality of life better than support provided by health professionals (Ruiz-Rodríguez et al., 2021). Support networks are invaluable resources from which women can learn self-advocacy and provide camaraderie to those just beginning to learn strategies to improve their cancer- and treatment-related symptoms (Hagan & Donovan, 2013a). Other benefits of acquiring the skill of connected strength include finding self-worth; managing relationships; supporting and drawing support from fellow patients with cancer; seeking assistance from family and friends; balancing the needs of others with one's own needs;

and protecting personal boundaries (Thomas et al., 2019). In the context of pain management, connected strength involves balancing pain management needs with providing support to others.

1.2.4.4 Applying the FSACS and Opioid Stigma frameworks

This study proposes the following relationships between the theoretical frameworks of Female Self-Advocacy in Cancer Survivorship (Thomas et al., 2020) and opioid stigma (Bulls et al., 2022):

1. **Both are negatively impacted by misinformation.** Public misconceptions and media representation increase the likelihood that a patient will experience opioid stigma (including self-imposed opioid stigma), impairing their ability to make informed decisions.
2. **Both frameworks recognize the vulnerability of marginalized populations.** Older women who endorse opioid stigma share sociodemographic and clinical characteristics with women who score low in self-advocacy (e.g. women of color, women of lower socioeconomic status). Older age may also be a contributing factor.
3. **Opioid stigma impedes effective communication with healthcare providers.** Perceived opioid stigma impairs patient/provider communication and causes patients to engage in avoidant behaviors (e.g., hoarding medications, avoiding provider visits and discussing pain during provider visits, declining recommendations to treat pain with opioids).
4. **Failure to self-advocate and perceived opioid stigma impair optimal quality of life.** Both opioid stigma and failure to self-advocate ultimately result in inadequate management of pain and other cancer-related symptoms, thus reducing quality of life.
5. **Self-advocacy may mitigate opioid stigma.** Pain management for patients who are socially marginalized is already challenging, and sociodemographic characteristics such as

race or ethnicity, sex or gender identity, and socioeconomic status of the patient may compound opioid stigma (Bulls et al., 2022; Craig et al., 2020). Self-advocacy may reduce the potential for cancer disparities in care and outcomes among individuals from marginalized groups (Street et al., 2019; Thomas et al., 2020).

6. **Opioid stigma impedes the self-advocating behavior of connected strength.** Perceived opioid stigma impairs connected strength by decreasing the likelihood that the individual will reach out for help with their problem of undermanaged/unmanaged pain for fear that their support systems (e.g., caregivers, care team, pharmacists, friends, family, fellow cancer survivors) will judge them for requiring opioids to manage their pain.
7. **Education empowers patients to self-advocate for needs such as adequately managed pain and avoidance of perceived opioid stigma.** Providing stigma-related knowledge informs pain management decision-making and decreases stigma (Bulls et al., 2022; Rao et al., 2019).

By clarifying the ways in which women aged 65 and older with breast cancer self-advocate for improved communication regarding unmet pain management needs, our findings add foundational research to improvement of the needs of a highly prevalent yet undermanaged population. The dissertation study builds on the current science of pain management by integrating a new concept – self-advocacy (Thomas et al., 2020) – to combat the high prevalence of unmanaged and undermanaged pain in women with breast cancer who are aged 65 and older. Findings from this study will also contribute to the body of evidence to support the conceptual framework of opioid stigma (Bulls et al., 2022) by exploring the unique challenges of managing pain in women aged 65 and older with early-stage breast cancer.

1.3 Innovation

The dissertation study is innovative in numerous ways:

1. Theoretically, this study is innovative as well as important because it is the first study to address pain management by applying the conceptual frameworks of female self-advocacy in cancer survivorship (Thomas et al., 2020) and opioid stigma (Bulls et al., 2022) to a cohort of women aged 65 and older with early-stage breast cancer.

2. Methodologically, this study is innovative due to its ability to utilize both qualitative and quantitative approaches to deeply and richly describe the impacts of opioid stigma and patient-centeredness of communications with healthcare providers on pain self-advocacy and pain management. To our knowledge, this is the first study to combine these methodologies and frameworks to explore these concepts in a population of women aged 65 and older with breast cancer.

3. Clinically, this study fills a research gap by directly addressing the role of opioid stigma caused by the ongoing opioid crisis in impeding pain management among women aged 65 and older with breast cancer. This will lead to future interventions aimed at addressing the high prevalence of undermanaged pain attributed to opioid stigma in women aged 65 and older with breast cancer.

2.0 Research Design and Methods

This descriptive, cross-sectional study explored the experiences and associations among factors that affect how well pain is managed among women aged 65 and older with early-stage breast cancer.

2.1 Methods for Aim 1

Aim 1. Explore the experiences and factors influencing pain management among women aged 65 and older who reported moderate to severe pain within the first year after breast cancer surgery.

2.1.1 Design

Aim 1 employed qualitative description to describe the experience of pain management from the perspective of women aged 65 and older with breast cancer who report moderate to severe pain. Qualitative description (Sandelowski, 2000, 2010) was well-suited to presenting the findings of this first aim in that it:

typically combines varied techniques for the processes of sampling participants, collecting data, performing data analyses, and data presentation to capture deep, rich information and variations in participants' opinions.

is conducive to straightforward, minimally-theorized answers to research questions.

entails interpretation of the facts about the phenomenon of interest (e.g., perceptions of pain management) in order to describe it.

- presents these facts using everyday language (i.e., the language used by the participants).

2.1.2 Sample

Several sampling techniques were used to select women from the parent study for participation in Aim 1. Inclusion criteria for the parent study included diagnosis with an early-stage breast cancer (stages I, II, and IIIa) per the seventh edition of American Joint Commission Criteria for cancer staging (Edge et al., 2010) and being scheduled to undergo surgery for removal of the cancer under anesthesia (general or combined general and regional anesthesia). First, we employed criterion sampling, defined as sampling by seeking cases meeting some predetermined criterion (Creswell & Poth, 2018b) to choose women from the parent study who: 1) reached the age 65 or older as of March 1, 2021, and 2) reported experiencing pain at a level of "4" or above on the 0-10 Numerical Rating Scale (NRS) at any time during parent study participation (n=74). We chose the NRS score of “4” as a clinically meaningful cut-off point for moderate pain that interferes with functioning based on the findings of Boonstra et al. (2016). Applying these criteria maximized the achievement of an overall homogenous sample with similarities pertinent to our research question such as reaching age 65 or older and having reported at least one experience of undermanaged pain (Dicicco-Bloom & Crabtree, 2006). Secondly, we applied purposeful sampling by which the researcher selects individuals who can purposefully inform understanding of a proposed problem or question (Creswell & Poth, 2018b) to select all women of color (n=8) from the 74 eligible parent study participants. We invited these women to participate with the

intention of increasing racial diversity amongst the sample in an effort to obtain data that is representative of women belonging to this group (Sandelowski, 1995). Thirdly, we applied reputational case selection, a sampling technique in which the researcher selects cases based on the recommendations of an expert or key informant (Miles & Huberman, 1994), to the remaining 66 eligible individuals by identifying: 1) those most active in the parent study, and 2) those considered by research associates to be illustrative of various pain management to ensure that findings adequately represented the target population.

2.1.2.1 Sampling procedure

Credible, reliable data reporting in qualitative research is achieved by selecting participants who can provide information-rich responses about the phenomenon of interest (Patton, 2015). By applying the aforementioned sampling procedures, we identified 35 participants to approach for participation to increase the likelihood of reaching data saturation, the point at which interviews no longer yielded further insight (Creswell & Poth, 2018a) while providing a feasible number of interviewees for the study. Had data saturation not been achieved after interviewing the 35th participant, reputational case selection would have been applied to the remaining eligible participants (n=31) to identify individuals to approach for participation. Our team agreed that we reached data saturation after coding and discussing the transcript for the 21st interviewee.

2.1.2.2 Recruitment procedure

Recruiting began after obtaining Institutional Review Board (IRB) approval from the University of Pittsburgh's Human Research Protection Office. Recruiting began in March 2021 and ended in June 2021. We approached study participants by the preferred communication method they indicated in the post-discharge survey of the parent study, either via email or tele-

phone. Study team members followed IRB-approved scripts to recruit each participant, which are located in Appendices A through C. Of the 35 individuals approached, three declined participation. The first gave as her reason "that would take too long;" a second expressed disinterest in participation due to a recent knee replacement; and a third individual declined because of complications from her spinal stenosis and peripheral neuropathy. Three individuals initially agreed to participate but withdrew prior to being interviewed. One individual had agreed to participate if needed but declined at the time approached due to complications from her treatment for liver metastases. A second individual withdrew due to her husband's acute critical illness, and another withdrew during the consent process after realizing her interview would be audio-recorded. After three attempts, four individuals did not respond to recruitment emails, and another four did not answer their telephone calls. Of the 21 interview participants, seven were non-Hispanic Black, and the other 14 were non-Hispanic White. Those who agreed to participate set a mutually convenient date and time with the recruiting study team member to conduct the telephonic interview. K.A. then sent a reminder letter (Appendix D) for each appointment as well as a written form of the study consent (Appendix E) to be reviewed with them immediately prior to their interview.

2.1.3 Qualitative data collection

2.1.3.1 Interview process

An expert in qualitative research (Dr. DeVito Dabbs), from whom K.A. received academic instruction and mentoring, guided data collection. K.A. trained two research assistants from the parent study (C.H. and S.P.) in qualitative data collection procedures, including leading one-on-one interviews; discussing sensitive topics; and ensuring qualitative rigor based on the model of trustworthiness of qualitative research constructed by Lincoln and Guba (1985). C.H., K.A.,

and S.P. then created an interview guide comprised of semi-structured interview questions (Creswell & Poth, 2018b) based on Aim 1. Questions focused on participants' descriptions of their personal pain experiences; perceptions of communications with their care teams, particularly when reporting changes in pain status; attitudes regarding use of opioids to manage pain; and obstacles they encountered in obtaining resources pertinent to cancer-related pain management, particularly an initial prescription or escalation of opioids. To increase reliability and validity of the interview guide, an experienced nurse practitioner who is also a woman with breast cancer over the age of 65 and did not participate in either the parent or the present study reviewed the first version of the interview guide, and K.A. altered the interview guide per her recommendations. K.A. conducted a mock interview using the first revision of the interview guide (Appendix F) with another woman with breast cancer over the age of 65 who participated in neither the parent nor the present study who volunteered to be interviewed. This provided an opportunity to trial the interview process using the revised interview guide, and the interviewee's responses guided the second revision to the interview guide (Appendix G).

Team members conducted all interviews via telephone from a private location to ensure confidentiality of participant responses. As directed by the IRB, prior to conducting each interview, the interviewer confirmed that the participant understood the consent form and asked each participant's permission to begin recording so that verbalization of the consent process and verbal agreement to proceed with the interview was audible in the recording. Once the participant verbalized understanding and consented to proceed with the audio-recorded interview, the interviewer asked questions of the participant employing the interview guide. At the conclusion of each interview, the interviewer transcribed the recording using voice transcription software. The interviewer then reviewed and corrected the transcript for accuracy, referring back to the record-

ing of the interview as needed. To limit inherent biases and reinforce the confirmability of our findings, the interviewers participated in the process of memoing to document thought processes that occurred at the time of the interview if needed for validation while performing the analyses (Creswell & Poth, 2018a).

After all three interviewers (one each by C.H., S.P., and K.A.) completed one interview each using the second version of the interview guide, the participants' responses were discussed among the team. K.A. sent this interview guide to Dr. DeVito Dabbs for recommended revisions. Guided by Dr. DeVito Dabbs' input, team members mutually determined which questions to eliminate or modify and those which achieved the study purpose as written to create the third revision to the interview guide (Appendix H). The team discussed the need for minor changes to this version, resulting in a fourth and final revision to the interview guide (Appendix I). Interviewers conducted the remaining interviews following this fourth version of the interview guide, as the team agreed during weekly meetings that the interview guide required no further revisions.

2.1.3.2 Data management

Each team member initially stored the recorded and coded data from the interviews and transcripts on their personal virus and password-protected laptops, separate from any identifiable data. Interviewers asked each participant's permission to use her first name throughout the interviews and on the interview transcripts labeled with her initials and parent study participant number. Once completed, team members transferred the transcripts and recordings to Dr. Wesmiller's secure network drive, maintained exclusively in the School of Nursing.

2.1.4 Qualitative analysis for Aim 1

2.1.4.1 Codebook development

All three interviewers (C.H., K.A., and S.P.) assisted by the PI's Undergraduate Research Mentoring Program (URMP) student (Y.Z.) reviewed and corrected the transcript for accuracy after each interview. The interviewers then shared their corrected transcripts with all team members for coding. The team initially consisted of the three interviewers and Y.Z.; however, after S.P. left the University of Pittsburgh, K.A. trained another research assistant from the parent study (E.K.) in recruiting and coding to replace S.P. for the last month of the study. Of the 21 interviews performed, C.H. conducted one interview, S.P. conducted two, and K.A. conducted the remaining 18. Interviews took place between March and June 2021 with team meetings beginning in March and ending in July 2021. Team members applied the open coding technique to each transcript as recommended by Creswell and Poth (2018a) wherein codes are emergent rather than prefigured, leading to rich responses that reflect participants' lived experiences. The team met via videoconference after each round of interviews to discuss the coded transcripts and to modify the codebook as needed. Y.Z. recorded minutes for each meeting and uploaded them to the team's university-maintained drive. At each meeting, the team updated the initial codebook through constant comparative analysis (American Psychological Association, 2020), an iterative process of reducing the data by comparing codes across all interviews (Glaser & Strauss, 1967), to identify participants' significant statements and patterns to incorporate into an evolving codebook. The team members coded subsequent transcripts by applying each newly-created version of the codebook incorporating the new codes agreed upon by all team members after discussing any disagreements among the three coders to achieve consensus. Decisions during these meetings included: 1) whether the interview questions accomplished the purpose of the study

adequately; and 2) whether changes to the coding process and additions to the codebook were warranted. Y.Z. recorded minutes of these meetings including recommended changes to the codebook, and K.A. reviewed these after each meeting to maintain validity and rigor in the process and to contribute to the study's audit trail discussed later in this document. The team continued these meetings and revisions until achieving data saturation, the point at which no new codes emerged from the interview transcripts (Creswell & Poth, 2018a). The team mutually agreed upon data saturation after coding and discussing the 21st interview transcript, and recruiting for the study ended. K.A. mailed "thank you" notes to each participant who completed an interview and added $25 to each participant's payment solution card designated for medical study participants by the University of Pittsburgh (except one participant who declined the gift). This process yielded the initial codebook found in Appendix J.

2.1.4.2 Qualitative data analysis

All coded transcripts were uploaded to NVivo® Version 12 Qualitative Data Analysis (QDA) software. K.A. performed the final steps of analysis in consultation with A.D.D. All coded transcripts were reviewed and recoded if necessary based on the final version of the codebook, resulting in a final codebook located in Appendix K. Thematic analysis was performed following the steps recommended by Braun and Clarke (2006, 2012) by collapsing related codes under themes, then identifying the categories around which themes clustered. From these analyses, three categories emerged: facilitators of optimal pain management, challenges to optimal pain management, and other factors affecting optimal pain management (e.g., effects of cancer treatment modalities, internal/external influencers, types of/methods for analgesia).

2.1.4.3 Qualitative rigor

We maintained qualitative rigor according to the recommendations of Thomas and Magilvy (2011), which are based on the model of trustworthiness of qualitative research proposed by Lincoln and Guba (1985) comprised of four components: 1) credibility, 2) transferability, 3) dependability, and 4) confirmability. According to Thomas and Magilvy (2011), credibility in qualitative research is comparable to internal validity. Credibility was demonstrated by time spent and the investment of more time reviewing interview transcripts repeatedly to find commonalities among study participants; using participants' own words to much as possible during final results reporting; allowing for member checking, in which data are reviewed by participants to establish validity (Cohen & Crabtree, 2006); and by employing thick description in which we explicitly identified patterns and relationships within our findings to provide context and trustworthiness to our results (Holloway, 1997). Transferability, which Thomas and Magilvy equate to external validity, refers to evidence provided by the researcher that findings will be applicable in other contexts with other study participants. We demonstrated transferability by fully describing our sample when reporting results including factors such as age, race/ethnicity, surgical and treatment types. Dependability is comparable to reproducibility and reliability of a study, per Thomas and Magilvy. This component was embodied in maintaining an audit trail as described below as well as by providing detailed descriptions of the research methods utilized to conduct this study including the use of a semi-structured interview guide and use of the constant comparative method as previously described to improve the team codebook. The fourth component of Lincoln and Guba's model, confirmability, was met by prolonged engagement, as we have developed rapport and trust with our participants to better understand our phenomenon of interest (Cohen & Crabtree, 2006). Meeting minutes recorded by Y.Z. during team meetings re-

flecting decisions and discussions amongst the team further enhanced the confirmability of the findings of our qualitative analyses. Evidence of trustworthiness of the results was provided through reflexivity and bracketing. Reflexivity is described by Lincoln and Guba (1985) as systematically giving attention to the context of knowledge construction, particularly the researcher's influence, during all steps of the research process while bracketing involves the investment of preparation, action, evaluation, and systematic feedback about the effectiveness of the qualitative process (Ahern, 1999). Reflexive bracketing was evidenced by the interviewers' self-critical attitudes such as the insights provided in the recorded memos of perceptions and biases experienced before, during, and after each interview, which were also discussed during weekly team meetings, and the researcher continued this by evaluating the analytic process as it progressed and will continued to do so during and after presentation of the findings.

To further ensure qualitative rigor, we followed the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines established by Tong et al. (2007), a framework for comprehensively reporting key aspects of qualitative research in three domains: research team and reflexivity; study design; and data analysis and reporting. Appendix L is the current COREQ checklist for this study that was continually updated through the end of the dissertation study.

2.1.4.4 Provision of an audit trail

The criteria for an audit trail as designated by Thomas and Magilvy (2011) include: 1) specific statement of the purpose of the study; 2) extensive discussion as to how and why participant selection occurred; 3) detailed descriptions of the length and breadth of data collection; 4) thorough explanation of transforming the raw qualitative data into coding units for qualitative analyses; 5) deep discussion of the reasoning behind interpretation and dissemination of research results; and 6) clear communication of the strategies employed to ensure data credibility. To

meet these criteria, the purpose of this study is clearly stated in Aim 1. The Sample Procedure, Sample Justification, and Recruitment Procedure sections of this paper outline participant selection. The Interview Process described above details the data collection process. We further built on this audit trail by describing how we further refined our draft codebook into a finalized codebook divided into themes; discussing how our findings complemented, added to, or further explained our research aim as currently described in the literature; and demonstrating transparency in reporting by thoroughly describing how we arrived at our findings. Supporting materials we maintained but filed independently of the confirmability audit trail included raw data (interview transcripts and field notes); evidence of the analyses conducted by the investigators (all versions of the codebook, coded transcripts); and findings (analytic descriptions, figures, and other displays) (Wolf, 2003).

2.2 Sampling and Procedures for Quantitative Aim (Aim 2)

Aim 2. Describe the associations among self-reported: 1) levels of self-advocacy; 2) patient-centeredness of communications with healthcare providers; 3) stigma regarding opioid use and addiction; and 4) ratings of pain intensity among a cohort of women with breast cancer aged 65 and older.

2.2.1 Design

This cross-sectional study incorporated a descriptive, correlational design to explore associations among study participants' self-reported measures of ability to self-advocate for their

needs; perceived patient-centeredness of interactions with cancer care team providers; opioid stigma; and current pain intensity.

2.2.2 Sample

2.2.2.1 Sample selection from parent study

For Aim 2, participants selected for recruitment from the parent study (N=356) were age 65 or older and completed at least one year of data collection in the parent study as of May 1, 2022. Inclusion criteria for the parent study required the diagnosis of early-stage breast cancer, classified as stage I, II, or IIIa per the seventh edition of the American Joint Committee on Cancer (AJCC) staging criteria (Edge et al., 2010); no clinical evidence of distant metastases; and scheduled breast surgery lasting 4 hours or less. Exclusion criteria included a previous history of neurologic conditions, such as stroke, head injury, spinal cord injury, and intracerebral hemorrhage, and scheduled for a surgical procedure anticipated to last more than 4 hours.

2.2.2.2 Sample size justification

In the absence of good effect sizes, for the correlation analyses, we applied conventional criteria for behavioral sciences (Cohen, 1988) to estimate sample size for adequate power. Employing the G*Power® 3.1.9.2 statistical analysis program (Faul et al., 2009) to estimate sample sizes for the correlation analyses, with power level set at 0.8 and alpha-level set at 0.05., to detect a medium effect size (r=0.3), the recommended sample size was 64 participants. Effect sizes and achieved power will be computed from the collected data to inform future studies.

2.2.2.3 Sampling procedures

All parent study participants aged 65 or older as of May 1, 2022 who completed at least one year of data collection in the parent study were approached to participate (n=144). Eighty-three participants expressed interest in participating, and 73 participants completed data collection, meeting and exceeding the recommended sample size of 64 participants.

2.2.2.4 Recruitment procedure

The recruiting process employed for this study is shown in Figure 2. Individuals who met inclusion criteria were approached for participation by their preferred communication method (i.e., telephone call or email) indicated during parent study participation. Those who expressed interest in participating and gave consent either verbally or via email following the procedure specified by the University of Pittsburgh's IRB to participate were either physically or electronically mailed a study packet. The study packet contained an introductory letter with detailed instructions for completing and returning the questionnaire; a written copy of the consent form; and the 37-item questionnaire containing four instruments: the 20-item Female Self-Advocacy in Cancer Survivorship scale (FSACS scale); the six-item Patient-Centered Communication in Cancer Care instrument (PCC-Ca-6); eight items from the Brief Opioid Stigma scale; and the current Patient-Reported Outcomes Measurement Information System Scale for Pain Intensity (PROMIS® Scale v2.0 – Pain Intensity 3a). Those who were reached yet declined to participate (n=7) were asked to give their reasons for doing so. Reasons included illness, discomfort with questions, being too busy, and having no desire to participate. Two dropped out after receiving the questionnaire expressing discomfort with questions. Five failed to return the questionnaire or respond to follow-up telephone calls or emails after consenting. The remaining 57 eligible parent

study participants did not respond to recruitment materials sent through the postal service or to recruiting emails or telephone calls.

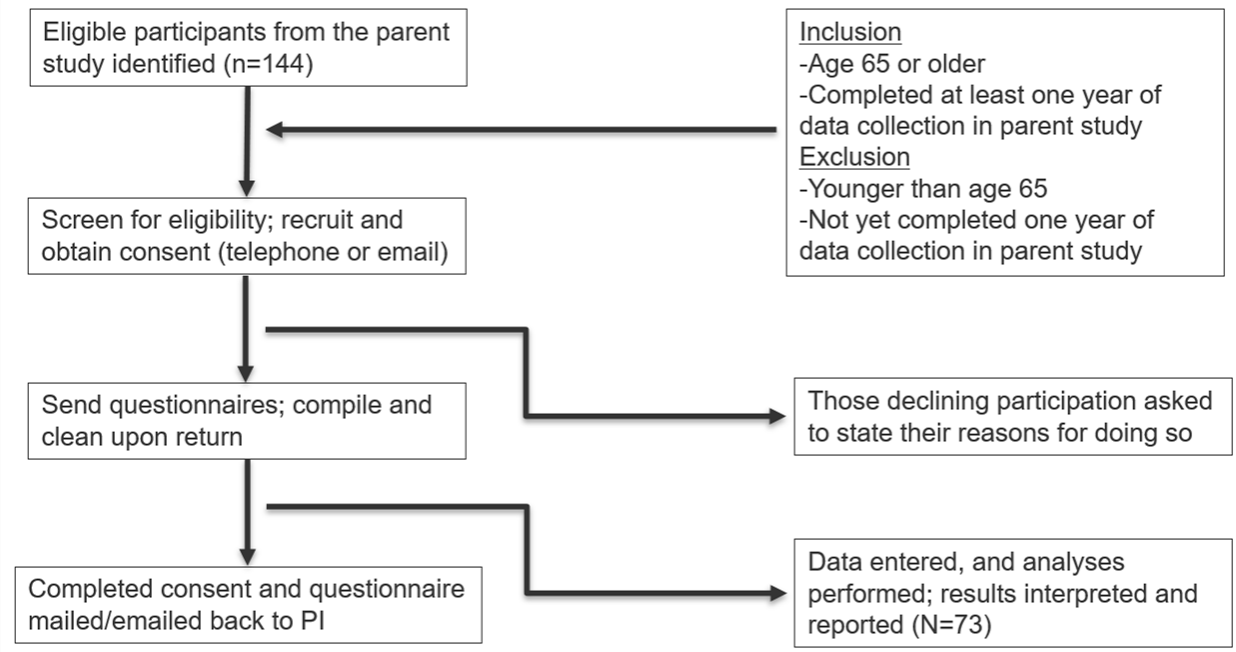

Figure 2. Flowchart of recruitment for quantitative aim (Aim 2)

2.2.3 Instrumentation

2.2.3.1 Female Self-Advocacy in Cancer Survivorship scale

The Female Self-Advocacy in Cancer Survivorship (FSACS) scale was developed by Hagan et al. (2018a) to provide a theoretically-based measure of the ability of a woman with cancer to demonstrate behaviors that serve to meet her individual needs, such as eliciting support from and providing support to others; communicating important issues to her cancer care team such as unmanaged symptoms; and gathering information to optimize the outcome of her healthcare decisions. Scientific evidence gathered from a concept analysis of relevant literature (Hagan & Donovan, 2013b) and a focus group study (Hagan & Donovan, 2013a) informed in-

strument development. The initial iteration of the scale was piloted with a panel of professional and lay-experts in self-advocacy. To establish content validity, the content validity index (CVI) was calculated for each scale item and the scale as a whole based on Lynn's (1986) criteria which sets a minimum CVI of 0.78 (i.e., 7 of the 9 experts) to endorse significance of an item or an instrument beyond the alpha-level of .05 (Hagan et al., 2016). These criteria were met evidenced by a calculated CVI of 0.81 for each scale item and of 0.83 for the overall scale; items with low CVI, deemed as redundant and/or reflective of a self-advocacy outcome rather than behavior were eliminated (Hagan et al., 2016). Hagan et al. (2016) then pilot-tested this revised version of the scale with 40 adult female cancer survivors for internal consistency among the items and test-retest reliability of the instrument with repeated measures at baseline and again in two weeks to minimize variation of responses. Based on Cronbach's alpha measures for a sample size for N=40, the internal consistency was strong for the overall scale (α=.92) and for the three subscales (.88, .81, and .90, respectively); test-retest reliability as measured by Pearson's product-moment correlations based on n=39 was also strong for the overall scale (r=.94) and the three subscales at r=.85, .97, and .88, respectively (Hagan et al., 2016). Items that performed poorly under evaluation for content validity, reliability testing, and post-test cognitive interviewing of participants were targeted for potential deletion dependent upon the outcome of future testing.

The 57-item iteration of the FSACS scale underwent psychometric testing for construct validity by Hagan et al. (2018a) to measure its level of accuracy for making inferences about women's abilities to self-advocate. Determination of the construct validity of the FSACS scale was based on evidence of the scale's: (1) internal structure consistent with the underlying model of self-advocacy; (2) sensitivity to differences between groups known to differ in self-advocacy skills; (3) relationships between self-advocacy and key potential predictors (openness and con-

scientiousness; information engagement; social support) and outcomes (symptom burden and healthcare utilization); (4) relationships between self-advocacy and related concepts (patient activation; self-advocacy within another patient population); and (5) relationships between self-advocacy and criterion measures (Hagan et al., 2018a). Analyses included an exploratory factor analysis, *t*-tests, and bivariate correlations using validated, reliable measures for constructs. Evidence from all five hypotheses supported the construct validity of the Female Self-Advocacy in Cancer Survivorship Scale (Hagan et al., 2018a).

The factor analysis confirmed the three underlying dimensions of self-advocacy resulting in a 20-item measure with strong internal consistency for each dimension that explained almost half of response variance (Hagan et al., 2018a) evidenced by Cronbach's alpha values as follows: Being an Informed Decision Maker (α=.82); Connected Strength (α=.85); and Communicating with My Healthcare Team (α=.79). Each of the scale's three dimensions are measured with a six-point Likert-type ordinal scale (1 = *strongly disagree* through 6 = *strongly agree)* (Hagan et al., 2016). The total score measure the patient's overall ability to self-advocate, whereas the subscale scores provide more specific information about areas in which they may struggle (Hagan et al., 2016). The higher the patients' score on these self-advocacy subscales, the less likely their symptoms are to interfere with their lives (Hagan et al., 2018a). Researchers interested in using this scale are permitted to administer it directly to individuals with cancer who may then complete it independently; published results must include the citation of the scale from the *Journal of Advanced Nursing* (Hagan et al., 2018a).

Scores for each of the scales' three dimensions were calculated per the instructions provided with the scale and based on participants' responses to the six-point Likert-type ordinal scales for each question (1 = strongly disagree through 6 = strongly agree) then totaled to deter-

mine patients' overall propensity for self-advocacy. Scores for each of the three dimensions of female self-advocacy in cancer survivorship were also evaluated.

2.2.3.2 Brief opioid stigma scale

The Brief Opioid Stigma Scale, designed by Yang et al. (2019), is a theoretically-based measure of opioid-related stigma among individuals with opioid use disorder (OUD). Psychometric testing of the scale reflected good initial construct validity when applied to a population of 387 inpatients participating in an opioid managed withdrawal program (Yang et al., 2019). It consists of 12 five-point Likert-type ordinal scale (*1 = strongly disagree; 3= unsure; 5 = strongly agree)* questions divided into three subscales: Stereotype Awareness; Stereotype Agreement; and Self-Esteem Decrement (Yang et al., 2019). Higher scores are indicative of higher propensity for the individual to ascribe to opioid-related stereotypes (Yang et al., 2019). As OUD is not a consideration in this study, the "Self-Esteem Decrement" subscale will be omitted from the questionnaire, as its items assess self-respect in individuals with an OUD. Questions from the Stereotype Awareness subscale focus on general beliefs about individuals addicted to opioids while items included in the Stereotype Agreement subscale focus on participants' perceptions of individuals addicted to opioids. To our knowledge, this study will be the first to apply the Brief Opioid Stigma scale to a population of women aged 65 and older with breast cancer whose opioid use status is unknown.

2.2.3.3 Patient-Centered Communication in Cancer instrument (Short Form) – PCC-Ca-6

The six-item Patient-Centered Communication in Cancer Care Instrument (PCC-Ca-6) contains six questions that assess each aspect of the six core functions of patient-centered communication: 1) fostering healing relationships; 2) facilitating the exchange of information; 3) re-

sponding to emotions; 4) managing uncertainty; 5) making decisions; and 6) enabling patient self-management (Epstein & Street, 2007). The instrument employs five ordinal measures, depending on the wording of the question: frequency (1=never, 2=rarely, 3=sometimes, 4=often, 5=always); amount (1=not all, 2=not very much, 3=somewhat, 4=a lot, 5=a great deal); and quality (1=poorly, 2=not very well, 3=fairly well, 4=very well, or 5=outstanding); the mean scores for each group are then calculated and averaged to obtain an overall communication score (Reeve et al., 2017). Psychometric testing revealed reliability scores within each function ranging from .90 to .96, and the six-question PCC-Ca-6 yielded an overall reliability score of .92 (Reeve et al., 2017).

2.2.3.4 PROMIS® Scale v2.0 – Pain Intensity 3a

Patient-Reported Outcomes Measurement Information System Scale for Pain Intensity (PROMIS® Scale v2.0 – Pain Intensity 3a) developers utilize rigorous methodologies known as item banks to develop measures such as the PROMIS® Scale v2.0 – Pain Intensity 3a and test their validity ("PROMIS Pain Intensity - Scale and Scoring," 2020). The domain team constructed this three-item scale (3a) with a focus on representing the full range of possible pain intensity. It is scored using Item Response Theory (IRT), a family of statistical models that link individual questions to a presumed underlying trait or concept of pain intensity ("PROMIS Pain Intensity - Scale and Scoring," 2020). Domain experts provided input on the relevance of each item and utilized both psychometric properties and clinical input to finalize the scale. The measure includes three items rating pain from “Had no pain” = 1 to “Very severe” = 5. The first two items assess pain intensity over the past seven days while the last item asks patients to rate their pain intensity “right now.” The scale produces an IRT-based T-score and Standard Error. A higher PROMIS® T-score represents more of the concept being measured. For negatively-worded concepts like

Pain Intensity, a T-score of 60 is one standard deviation worse than average. By comparison, a Pain Intensity T-score of 40 is one standard deviation better than average ("PROMIS Pain Intensity - Scale and Scoring," 2020). Raw scores for each of the three items were totaled and the total scores converted to T-scores using the scoring table provided as an appendix to the scale.

2.2.4 Data collection

2.2.4.1 Data from the combined questionnaire

Participants choosing to complete paper versions of the questionnaire received hard copies of the consent form with which they verbally agreed along with the questionnaire while email participants received the same materials electronically. For the paper versions, a preaddressed, deidentified, stamped return envelope labeled with each participant's unique identification number and instructions not to include any identifying information were included in each study packet. Email participants received an electronic copy of the consent form along with a secure link to the questionnaire via the Qualtrics® online survey software platform (Qualtrics, Provo, UT). Participants were requested to complete and return the questionnaire no later than one week after receiving them. Participants choosing to receive the paper version of the survey received a reminder telephone call if surveys were not returned after one week and again after two weeks. Reminder emails were sent to participants who chose to complete the survey electronically yet did not respond one week after receiving the email and link to the survey. At the two-week timepoint, all participants who did not completed the survey received a reminder via postal delivery. If, after three weeks, the participant still did not responded, they received a final telephone call with a request to respond to the survey within a week, at which time responses were no longer be accepted. Nonresponses (n=5) were classified as "lost to follow up."

2.2.4.2 Data management

Response data from each questionnaire was visually verified for accuracy and manually entered by the researcher who contacted participants via their preferred communication mode to complete missing responses as indicated in the consent form. An Undergraduate Research Mentoring Program (URMP) student (J.X.) double-entered 20% of the data to verify accuracy resulting in an error rate less than 1%. Once all data were compiled and corrected for accuracy, analyses were performed using IBM® Statistical Package for the Social Sciences (SPSS®) for Windows, Version 27 (IBM, 2020) and results reported with guidance from a quantitative methods expert (Dr. Paul Scott). All deidentified electronic data are stored in a password-protected computer, and the deidentified hard copies of completed questionnaires are stored in a locked file cabinet in the locked office for the parent study. All personal identifiers for the data are stored in a secure drive maintained within the School of Nursing.

2.2.5 Data analyses

All data analyses were performed using SPSS®. Table 2 lists the measures included in the study.

Table 2. Measures included in the study

Variable	Instrumentation		
	Measure	**Description**	**Response Options**
Self-Advocacy	Female Self-Advocacy in Cancer Survivorship scale	A 20-item scale consisting of three subscales: 1) Informed decision-making (6 items). 2) Effective communication (7 items). 3) Connected strength (7 items).	• 6-point Likert scale: 1 (strongly disagree) to 6 (strongly agree). • Higher scores indicate better self-advocacy skills.
Patient-Centeredness of Communications	Patient-Centered Communication in Cancer Care instrument (short form)	A 6-item scale: 1. responding to emotions 2. exchanging information 3. making decisions 4. fostering healing relationships 5. enabling patient self-management 6. managing uncertainty	• Five ordinal measures: frequency: 1 (never) to 5 (always); amount: 1 (not all) to 5 (a great deal); quality: 1 (poorly) to 5 (outstanding). • Higher overall scores indicate better communication.
Opioid Stigma	Brief Opioid Stigma Scale	A 12-item scale consisting of three subscales. • Two subscales were used: • Stereotype awareness (4 items). • Stereotype agreement (4 items).	• 5-point Likert scale: 1 (strongly disagree) to 5 (strongly agree). • Higher scores indicate greater stigma.
Pain Intensity	PROMIS® Scale v2.0, Pain Intensity 3a	A 3-item scale: worst/average pain intensity "in the past 7 days" and the pain level "right now".	• 5-point Likert scale: 1 (no pain) to 5 (very severe). • Raw scores converted to T-scores. Higher scores indicate greater levels of pain.

2.2.5.1 Descriptive statistics

As all variables included in Aim 2 were continuous, we described each variable according to measures of central tendency, mean and median, with respective measures of variability, standard deviation, and interquartile range. A histogram of each variable was also produced to illustrate the shape of the distribution of the data for each variable.

2.2.5.2 Data screening

Data accuracy (meaningfulness of the data) and completeness were checked at the time of data collection and data entry to ensure the quality of the data. Data coding and data entry were performed to check for discrepancies. 20% of the collected data were double-entered as previ-

ously described to verify accuracy. Data were recorded employing the Qualtrics® online survey software platform (Qualtrics, Provo, UT), imported into SPSS® (IBM, 2020), and exploratory data analyses performed to ensure that high-quality data were included in all the analyses (Day et al., 1998).

2.2.5.3 Assumptions checking

Assumptions of the planned Pearson correlation analyses among the four scales and their subscales to be included in this aim were assessed. First, scatterplots were generated to plot the residuals against linear fitted values and examined to check the assumptions of linearity and homoscedasticity. Upon visual inspection, if the scatter of datapoints on the graph was random, ovoid, and evenly dispersed, then linearity and homoscedasticity were assumed (Laerd, 2020a). Q-Q plots were also generated to check the assumption of normality in errors, and this assumption was considered to be met if the normal probability plot of the residuals approximated a linear distribution..

2.2.5.4 Outlier assessment

A box and whiskers plot was created for each scale variable and the whiskers examined for outlying values. SPSS® employs Tukey's Method to identify outliers and marks extreme outliers on the box and whiskers plots with asterisks. Three individual scores were identified as extreme outliers and excluded from the analyses.

2.2.5.5 Data analysis

SPSS® for Windows, Version 27, was employed to conduct all analyses for Aim 2. Descriptive statistics are reported as frequencies (n) and percentages (%) for categorical variables.

Scale variables were described with the mean, standard deviation, median, overall and interquartile range. Correlational analyses were conducted using Pearson *r* when assumptions of linearity, normality, homoscedasticity, and normality in errors were met. When these assumptions were violated, and the relationships between the variable pairs were monotonic (i.e., consistently moved in the same direction), we computed Spearman rho (r_s). Biserial correlation (r_b) was used when one of the variables was dichotomized. The level of statistical significance was set at an alpha level of 0.05.

2.3 Research Participant Risk and Protection

2.3.1 Human subjects protection

2.3.1.1 Human subject involvement

This prospective study involved participants aged 65 and older in the dissertation chair's comparative longitudinal cohort study, which has been approved by the University of Pittsburgh's Institutional Review Board (IRB) to deeply phenotype the nausea and vomiting experienced by women who have been diagnosed with breast cancer for three years following surgery as well as collect biological samples and use those samples to collect a variety of genomic and epigenomic data. The focus of the study is to understand the relationships among factors associated with unrelieved pain due to breast cancer and its treatment. These factors include self-advocacy, patient-centered communication, and opioid stigma. The target sample for this study are women aged 65 and older diagnosed with early stage (Stage I, II, and IIIa) breast cancer who

underwent curative breast cancer surgery at least one year ago through the University of Pittsburgh Medical Center (UPMC) Hillman Cancer Center Comprehensive Breast Program.

2.3.1.2 Risk of subject burden

Study participants were at risk of subject burden brought on by fatigue from the time invested in completing questionnaires and one-on-one interviews. Furthermore, questions posed during interviews and/or items on the questionnaire may have evoked unpleasant emotional experiences, such as recalling negative interactions with members of their cancer care team or fear of being stigmatized for employing opioids for pain management.

2.3.1.3 Inclusion of women

This study exclusively enrolled women aged 65-90. Breast cancer occurs rarely in men, accounting for only 1% of breast cancers in the United States (Demoor-Goldschmidt et al., 2018). These statistics have remained unchanged for 30 years. Moreover, the natural history of breast cancer in men is different from the disease course in women (Zehr, 2019). Furthermore, self-advocating behaviors in men differ significantly from those of women. A study conducted by Thomas et al. (2021) concluded that, unless an unresolved health-related problem is deemed a "major concern," men tend not to reach out to their healthcare providers for assistance with its resolution. However, Hagan et al. (2018b) found that women who endorse the ability to communicate needs and priorities to their healthcare providers tended to experience less symptom burden. Thus, the dissertation study focused on women with breast cancer.

2.3.1.4 Inclusion of individuals across the lifespan

This study exclusively enrolled women aged 65-90. In this study, we chose to focus on older women, as we have seen an increase in the number of women aged 65 years and older scheduled for breast cancer surgery (Kudach et al., 2018). The incidence of young girls under the age of 20 years diagnosed with breast cancer is extremely rare, occurring in less than 1% of this age group. (0.1/100,000) (Cardoso et al., 2012; Demoor-Goldschmidt et al., 2018).

2.3.1.5 Inclusion of minorities

The ethnic composition of Allegheny County (Census Bureau, 2020) was reported for 2020 to be 79.9 % Caucasian, 13.4% African American, 4.2% Asian American, 0.2% American Indian, and 2.3% Hispanic. We recognize that without oversampling and a directed minority recruitment plan, less than 15% of the eligible sample were minorities, predominantly African American. Thus, the parent study has a plan in place to increase the diversity of its sample that increased minority recruitment in the last year of the parent study. Dr. Margaret Rosenzweig is internationally known for her work focused on disparity in the treatment of African American women with breast cancer. She continues to collaborate with the parent study team as a consultant sharing her successful strategies on recruiting a diverse population. In addition, accrual in the parent study occurred at Magee Womens Hospital and UPMC East in Monroeville, PA. Both are hospitals in the UPMC Health Care System and aligned with the UPMC Hillman Cancer Center Comprehensive Breast Care Program. To ensure diversity is more than consistent with the composition of Western Pennsylvania in the parent study sample, minority recruitment was tracked and addressed at regular research team meetings to monitor progress and discuss strategies for modification of the recruitment plan when necessary.

2.3.1.6 Sources of materials

All completed instruments and interview transcripts are stored by the assigned study identification number, and all data will be presented and published in aggregate only. Recordings of interviews were stored on password and anti-virus protected computers. All identifiers are removed from study records. Information linking these code numbers to the corresponding subject identities are kept in a separate secure location which will remain for seven years after parent study participation in the School of Nursing and will not become part of a patient's health record.

2.3.1.7 Potential risk and protection against risk

To minimize the potential breach of confidentiality of data and participant anonymity, all subjects were assigned a unique code number located in the parent study's secure drive maintained by the School of Nursing. Security of data was upheld through the use of password protection and restricted access to users. Consent forms are retained in a discrete locked file cabinet in the parent study's secure office, and a list of the match between subject names and participant numbers are located in the parent study's secure drive maintained by the School of Nursing. Prior to contact with any subject of any data, all staff are required to sign a confidentiality agreement and to complete the following online modules from the Collaborative Institutional Training Initiative (CITI) sponsored by the Research Conduct and Compliance Office of the University of Pittsburgh: 1) Responsible Conduct of Research, 2) Human Subjects, and 3) Conflict of Interest. In addition, they are required to complete the HIPAA modules from Internet Based Studies in Education and Research (ISER) and complete Conflict of Interest disclosures. This is not a clinical trial; however, the researcher met with the dissertation committee co-chairs on at least a monthly basis to discuss data quality, data management and safety procedures, and any potential adverse events that could have occurred in the process of conducting the study. A committee re-

views the collection and integrity of data for the parent study, and the activities for the present study were incorporated into their efforts.

2.3.1.8 Risk of subject burden

To reduce the risk of subject burden for Aim 1, participants were given the option to stop participation at any time during the interview by hanging up the telephone or by verbally stating they have nothing else to say. Participants were informed that, if either situation were to occur, the interview would be deleted, and the information provided up to that point would not be utilized. Participants were encouraged before beginning the interview to tell the investigator to stop the interview if breaks were needed. To reduce the risk of subject burden for Aim 2, instruments involved in the study were mailed either in paper form or electronically to study participants with instructions to complete at a pace that was comfortable to them. The instructions also included the directive to take time to rest and resume the questionnaires at a later time, if fatigue and/or emotional distress were experienced while completing the instruments. Study participants were reminded that survey responses are not sent to their healthcare providers. If they experienced bothersome emotional symptoms, they were advised in the consent form to contact their health care team. It is estimated that the time to complete the survey was a maximum of 20 minutes.

2.3.1.9 Recruitment and informed consent

Participants were recruited from the parent study. After identification of eligible participants, the researcher ensured that individuals met the study eligibility criteria and were willing to participate. For those individuals willing to participate, detailed information regarding the study design and procedures (e.g., the purpose of study, risk/benefits, nature of questions asked, time

commitment) was provided and all questions answered prior to signing consent. Participants are not likely to receive direct benefit from participating in the study.

2.3.2 Importance of knowledge to be gained

Participation in this minimal risk study increased the understanding of the deeper meaning behind pain management self-advocacy, patient-centered communication, and opioid stigma. With this new knowledge, we will be able to empower women aged 65 and older with breast cancer to better manage pain associated with breast cancer and its treatment.

3.0 Summary of study

3.1 Changes to proposed study

This section is intended as a bridge between the proposed study, as approved by the committee following the Comprehensive Exam and Overview, and the actual study as it was conducted. These changes and the rationale for each are provided below.

3.1.1 Qualitative analysis (Aim 1)

As presented in the Comprehensive Exam and Overview, finalized versions of the transcripts were to be reviewed and recoded, if deemed necessary, by C.H. and K.A., using the emerging codebook to be modified per the recommendations of Dr. DeVito Dabbs. Final analyses were completed by K.A. in consultation with Dr. DeVito Dabbs. All coded transcripts were reviewed and recoded as necessary employing the iteratively-created version of the codebook as shown in Appendix J. A final version of the newly-created codebook was created from these repeated codings and is located in Appendix K.

After this step, rather than running matrix coding queries using qualitative data analysis software to identify themes within the coded data as proposed, K.A., in consultation with Dr. DeVito Dabbs, conducted thematic analysis following the steps outlined by Braun and Clarke (2006) by collapsing related codes under themes, then identifying the categories around which themes clustered. According to Braun and Clarke, thematic analysis minimally organizes the data and describes the dataset in rich detail, which aligns with qualitative descriptive methodology

wherein research phenomena are studied without preconceived classification (Sandelowski, 2000, 2010). Findings were reported by calculating the percentage of participants whose responses were coded to each of the identified themes. Findings are reported in the qualitative manuscript found in Section 5.0. Measures to maintain qualitative rigor per COREQ guidelines were followed as outlined, and the updated checklist is displayed in Appendix L.

3.1.2 Quantitative analysis (Aim 2)

We requested a modification to the IRB proposal (Appendix N) to request that participants who did not complete questionnaires three weeks after they were sent could receive a telephone call from the researcher requesting that the questionnaires be conducted verbally to reduce missingness of response data. We also employed IBM® Statistical Package for the Social Sciences (SPSS®) for Windows, Version 27 (IBM, 2020) rather than Version 26 to perform the analyses. Results of this study are displayed in the quantitative manuscript located in Section 6.0.

3.2 Summary of Dissertation

This dissertation study has several strengths. The literature supports our finding from our quantitative study of undermanaged pain in 41% of this sample of women aged 65 and older who were treated for early-stage breast cancer who are at least one year out from breast cancer surgery. We learned from our participants in the qualitative study, also women aged 65 and older treated for early-stage breast cancer whose interviews took place ranging from 0.23 to 2.56 years following initial breast surgery, that most of their pain is musculoskeletal in nature and mainly

attributed to adverse effects of aromatase inhibitors or chronic conditions comorbid with their breast cancer such as arthritis. To our knowledge, this is the first study to specifically explore the reasons for ongoing undermanaged pain in a population of older women with breast cancer, including lack of patient-centered communication with their cancer care teams; the influences of opioid stigma; and the need to develop and enact self-advocacy skills, including informed decision-making, effective communication, and connected strength. Ongoing exploration of these factors among different populations of adults aged 65 and older with breast cancer at different timepoints in their cancer trajectories will provide insight into targeting barriers to undermanaged pain and result in optimal quality of life.

Limitations to this study include reliance on the ability of participants in our qualitative study to recall past pain experiences and pain mitigation strategies and the limited generalizability of the findings due to homogeneity of race and ethnicity among our sample. However, our findings are valuable, as they elucidate factors that can be targeted to optimize pain outcomes for women aged 65 and older treated for breast cancer.

In conclusion, this dissertation study contributes to the understanding that, despite current technological advancements and availability of resources, undermanaged pain is an ongoing problem among women aged 65 and older treated for breast cancer. As the world's population continues to age, it is of the utmost importance to discover strategies and interventions that target undermanaged pain that are especially feasible for pain management among adults aged 65 and older. Both the qualitative and quantitative findings of this dissertation study provide foundational data to an ongoing research trajectory for managing pain for patients with cancer regardless of their demographic factors or stage in their cancer care continuum.

4.0 Manuscript 1: Older women and opioid analgesia after breast cancer surgery

Presented here is the full-text version of the manuscript accepted for publication, which was subsequently published in *Pain Management Nursing: The Official Journal of the American Society for Pain Management Nursing* and is available at:

https://www.sciencedirect.com/science/article/pii/S1524904220302496

4.1 Abstract

Purpose: To explore which factors influence opioid analgesia use in older women during the 48-hour period following hospital discharge after initial breast cancer surgery.

Design: This cross-sectional, descriptive study involved a cohort (n=57) of older women recruited for a larger study of breast cancer patients.

Methods: We gathered patient-reported data pertinent to perioperative and post-discharge pain control. Data were analyzed using linear regression to explore those characteristics that had the greatest influence on the amount of post-discharge opioid analgesia required.

Results: Following hospital discharge, 29 (51%) older women with breast cancer avoided opioid analgesia for several reasons. The number of prescribed opioid tablets each woman self-administered determined the total dosage of analgesia required 48 hours post-discharge.

Conclusions: The majority of this sample of older women with early-stage breast cancer experienced adequate pain relief following surgery and required little or no postoperative and/or post-discharge opioid analgesia.

Future Studies: Optimization of the pain control experience for older women with breast cancer requires thorough pain assessment from diagnosis through survivorship through the end of life. This can be achieved by equipping women in this population to advocate for their pain control needs in real time. Future studies that elucidate preferences, beliefs, and current pain control practices before, during, and after breast cancer surgery will improve safety and efficacy of pain control for this fast-growing population.

4.2 Background

Many women with breast cancer will undergo surgery at least once during the course of their treatment, as surgery is the definitive treatment for malignancies of the breast (Warburton et al., 2018). Up to 60% of patients endure persistent pain following breast cancer surgery, resulting in reduced overall quality of life and impaired function (Wang et al., 2018). Breast cancer surgery patients are at risk for complications that predispose them to persistent postoperative pain, including uncontrolled postsurgical pain; fluid collections in the wound with subsequent drain placement; and development of fistulae and/or adhesions (Feeney et al., 2018).

Among women diagnosed with breast cancer, over 50% are older than 60 (Varghese & Wong, 2018); therefore, a greater number of older women will undergo surgical intervention for breast cancer than their younger counterparts. As age increases, the risk of having other comorbidities as well as surgical risk itself increases, potentially leading to more complications (Wasif et al., 2019). Of note, older women may be at risk for carrying a higher postoperative pain burden that necessitates treatment with opioid analgesia, which includes both synthetic analgesics and those derived from opium. In their study of postoperative pain in older women following breast surgery, Kudach et al. (2018) found that women aged 60 and older reported higher pain scores (an average of 4.47 out of 10) than their younger counterparts ranging in age between 37 and 59 (3.77 out of 10). Pagán (2018) reported that women of all ages generally report pain more frequently with higher pain scores and endure pain longer than men. In a study of cancer-related pain, Fairchild (2010) found that patients over 65 years of age suffer from more uncontrolled pain, and women report significantly higher pain intensity; lower satisfaction with pain control; lower adherence to prescribed analgesics; and a higher tendency to stop medications when they are feeling better. Older adults are hesitant to discuss escalations of their pain (Kahana et al.,

2009; Makris et al., 2015), not realizing its undertreatment results in chronic pain and impairs functionality and quality of life (Bouri et al., 2018; Ruben et al., 2018). As older adults progressively age, degenerative processes such as osteoarthritis, spinal degeneration, declining immune competence (causing neuropathic pain and post-herpetic neuralgia), and a higher prevalence of cancer predispose them to suffer from uncontrolled pain—this insufficiently treated pain interferes with everyday physical, cognitive, and social competence, thus limiting quality of life (Eiche & Schache, 2016). Eiche and Schache elucidate that, although pain prevalence is higher with older than with younger adults, older adults receive significantly less analgesia for varied reasons including clinicians' uncertainties regarding treatment of pain and complications in eliciting pain information, particularly from cognitively affected patients.

While collecting data for the parent study, we noted that older participants often elected not to take opioids following surgery, even though they were prescribed. In this secondary analysis, we sought to explore postoperative pain experiences in older women after breast cancer surgery. We questioned whether the reasons women avoided postoperative opioid analgesia included fear of addiction, stigma, and/or its adverse effects, including nausea, constipation, and somnolence.

A component of the parent study examines the variability of postoperative nausea and vomiting and co-occurring symptoms, including pain, in women aged 18 to 90 undergoing surgery for early stage breast cancer. For this project, we focused on a subsample of women who are age 65 or older. The purpose of this study was to explore the factors that influenced the amount of opioid analgesia older study participants utilized during the 48-hour period following hospital discharge after breast cancer surgery.

4.3 Methods

4.3.1 Design

The present study was a secondary analysis of data from an ongoing study approved by the Institutional Review Board at the University of Pittsburgh. We employed a cross-sectional cohort study design (Hudson et al., 2005). All study participants from the parent study who were age 65 and older were included in this cohort of women with early-stage breast cancer. We then retrospectively assessed the outcome of each study participant's pain experience and employed these data to discover the characteristics of older women with breast cancer who required opioid analgesia following discharge from the post-anesthesia care unit (PACU) and those who did not require opioid analgesia during this time period.

4.3.2 Setting

A member of the research team recruited and consented participants and collected baseline data in the preoperative holding area of a large teaching hospital specializing in the care of women, which houses a nationally-known comprehensive Breast Care Program. Data were also collected at a community hospital affiliate where the same group of surgeons practice. Prior to recruiting and consenting patients to the parent study, research associates received extensive instruction on participant recruitment and data collection procedures specific to the study. Following surgery, research associates collected information regarding pain, nausea, vomiting, and medications administered during the PACU stay. Data pertaining to the 48-hour postoperative

period were collected via follow up telephone calls to each study participant by research associates using surveys designed specifically for the parent study.

4.3.3 Sample

Inclusion criteria for the parent study required the diagnosis of early-stage breast cancer, classified as Stage I, II, or IIIa per the American Joint Committee on Cancer staging criteria (Edge et al., 2010); no clinical evidence of distant metastases; and scheduled to undergo breast surgery lasting four hours or less. Exclusion criteria included a previous history of neurologic conditions such as stroke, head injury, spinal cord injury, intracerebral hemorrhage, and surgical procedures anticipated to last greater than four hours. For this secondary analysis, only data from study participants aged 65 or older were used.

4.3.4 Variables and procedures to collect data

4.3.4.1 Age, race, and ethnicity

Demographic data were collected by the research team in the pre-operative holding area. Study participants self-reported age, smoking status, and history of postoperative nausea and vomiting. In addition, they reported race/ethnicity as either Caucasian/White; African American/Black; Hispanic/Latino; Native American/Alaskan Native; Hawaiian/Other Pacific Islander; or Asian. For this secondary analysis, none of the study participants identifying as Hispanic/Latino, Native American/Alaskan Native, Hawaiian/Other Pacific Islander, or Asian met inclusion criteria for age.

4.3.4.2 Surgical procedures

Data regarding the specific surgical procedure performed were collected via chart review by a research team member. Surgical procedures included unilateral or bilateral total mastectomies in addition to unilateral or bilateral segmental, also called partial, mastectomies, and re-excisions due to inadequate margins from the first procedure. During their initial breast surgeries, most study participants also undergo sentinel node biopsies to assess for the presence of nodal metastases. Subsequent axillary lymph node dissection is indicated, if lymph nodes are positive; however, due to considerable progress in the surgical management of breast cancer, complete dissection is not often required in the low-risk population of patients with early-stage invasive breast cancer (Black & Mittendorf, 2013).

4.3.4.3 Preoperative medications

A member of the research team recorded the names and dosages of preoperative medications administered to each participant, if any.

4.3.4.4 Intraoperative anesthetic

Research team members reviewed participants' charts to determine the intraoperative medications each received. Anesthetics included desflurane; nitrous oxide; sevoflurane; sevoflurane with nitrous oxide; and, occasionally, Total Intravenous Anesthesia (TIVA).

4.3.4.5 Mean postoperative pain scores

Research associates recorded the time of admission and discharge for each participant during her PACU stay. The average length of PACU stay for 55 of the 57 older women included in this secondary analysis for whom PACU admission and discharge times were complete was

three hours and 34 minutes. Postoperative pain scores were assessed by the PACU nurse every 15 minutes while the study participant recovered in the PACU and each score recorded by a research team member. The PACU nurse asked each participant to rate her pain according to the 11-point (0-10) Numerical Rating Scale (NRS). Data from the literature portrays the NRS as a valid, reliable scale with excellent reproducibility in scoring exacerbations of pain reflected by a Cohen's Kappa value of K=0.80 with a 95% confidence interval between 0.61 and 0.91 (Brunelli et al., 2010). The research team member then recorded the participant's responses each time the nurse asked about pain level. Each study participant's average pain score (the sum of all recorded pain scores divided by the number of pain level queries) was included in the analysis.

4.3.4.6 Cumulative dose of PACU opioids

The cumulative dose of postoperative opioid analgesia each woman received is reported in morphine milligram equivalents (MMEs). A research assistant recorded each dose of pain medication administered and converted it to MMEs ("MME for Commonly Prescribed Opioids," 2019) per guidelines created by the Centers for Disease Control and Prevention (CDC).

4.3.4.7 PACU opioid type

A member of the research team recorded the name and dosage of opioid pain medication each participant received while in the PACU as the attending nurse administered the medication. Opioids received in the PACU include Dilaudid® (hydromorphone); OxyIR® (oxycodone 5 mg); and Sublimaze® (fentanyl).

4.3.4.8 48-hour pain scores

Members of the research team collected 48-hour pain scores as part of the post-discharge nausea and vomiting (PDNV) Survey via telephone two days following discharge from the PACU after breast surgery. Study participants reported pain according to the 11-point NRS.

4.3.4.9 48-hour opioid drug type

The types of opioid analgesia each woman self-administered is included in the PDNV Survey. These medications include OxyIR® (oxycodone 5 mg); Norco® (hydrocodone bitartrate 5 mg combined with acetaminophen 325 mg); Vicodin® (hydrocodone bitartrate 5 mg combined with acetaminophen 300 mg); Percocet® (oxycodone 5 mg combined with acetaminophen 325 mg); and Ultram® (tramadol hydrochloride 50 mg).

4.3.4.10 Number of opioid tablets taken at 48 hours

This variable is the result of the conversion of Number of Opioid Tablets Taken at 48 Hours into MMEs for each participant who required opioid analgesia.

4.4 Analysis

We employed a regression modeling approach to discover the factors that influence the amount of opioid analgesia older women with breast cancer utilize for pain management in the 48 hours following discharge. This is quantified by the outcome variable MME of Opioid Tablets Taken at 48 Hours. Using SPSS 25 (IBM SPSS Inc., Chicago, IL), we performed linear re-

gression using forward selection to determine which, if any, of the explanatory variables predicted the dosage of opioid analgesia this cohort reportedly self-administered during this time period.

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4.5 Results

4.5.1 Sample characteristics

Data describing the 57 women included in the current analysis are summarized in Table 3. These characteristics include age; ethnicity; surgery type; preoperative medications; intraoperative anesthetic; mean postoperative pain scores; type of opioid received while in the PACU; cumulative dose of opioids received in the PACU; pain scores 48 hours post-discharge; opioid drug types taken 48 hours post-discharge; and total number and dosages of prescribed opioid tablets taken 48 hours post-discharge.

Table 3. Summary of characteristics of both groups of study participants

Variable	Self-administered Opioids from Time of Discharge through 48 Hours after Discharge (N=28)	No Opioid Use from Time of Discharge through 48 Hours after Discharge (N=29)
Age (years)	**Mean = 71.36 ± 5.47** **95% CI (69.2 – 73.48)**	**Mean = 72.41 ± 4.82** **95% CI (70.58 – 74.25)**
65-70	15 (53.6%)	10 (34.5%)
71-74	7 (25%)	11 (38%)
75-80	3 (11%)	6 (21%)
81 or older	3 (11%)	2 (7%)
Race and ethnicity		
Black/African American	2 (7%)	2 (7%)
White/Caucasian	26 (93%)	27 (93%)
Surgical types		
Unilateral segmental mastectomy	20 (71%)	20 (70%)
Bilateral segmental mastectomy	1 (3%)	1 (3%)
Unilateral total mastectomy	6 (21%)	4 (14%)
Bilateral total mastectomy	1 (3%)	4 (14%)
Preoperative medications		
None	15 (53.6%)	16 (55.2%)
Fosaprepitant (Emend®) only	1 (3%)	4 (13.8%)
Fosaprepitant + acetaminophen	4 (14.2%)	2 (7%)
Fosaprepitant + scopolamine	2 (7%)	2 (7%)
Acetaminophen (Tylenol®) only	4 (14.2%)	3 (10%)
Acetaminophen + celecoxib (Celebrex®)	0	2 (7%)
Acetaminophen + perphenazine (Trilafon®) + Gabapentin (Neurontin®)	1 (3%)	0
Acetaminophen + perphenazine + gabapentin + celecoxib	1 (3%)	0
Intraoperative anesthesia		
Sevoflurane	19 (69%)	15 (52%)
Desflurane	1 (3%)	0
Nitrous oxide	2 (7%)	1 (3%)
Nitrous oxide + sevoflurane	4 (14%)	4 (14%)
Total IV anesthesia (TIVA)	2 (7%)	9 (31%)
Mean postoperative pain scores	**Mean = 3.71 ± 2.24** **95% CI (2.84 – 4.58)**	**Mean = 2.27 ± 2.22** **95% CI (1.43 – 3.12)**
0	5 (18%)	11 (38%)
1 – 1.9	0	3 (10%)

Variable	Self-administered Opioids from Time of Discharge through 48 Hours after Discharge (N=28)	No Opioid Use from Time of Discharge through 48 Hours after Discharge (N=29)
2 – 2.9	3 (11%)	3 (10%)
3 – 3.9	6 (21%)	4 (14%)
4 – 4.9	3 (11%)	3 (10%)
5 – 5.9	7 (25%)	3(10%)
6 – 6.9	2 (7%)	2 (7%)
7 – 7.5	2 (7%)	0
PACU opioid type		
None	7 (25%)	17 (59%)
Hydromorphone (Dilaudid®)	11 (39%)	8 (28%)
Hydromorphone + fentanyl (Sub-limaze®)	0	1 (3%)
Hydromorphone + oxycodone (OxyIR®)	2 (7%)	1 (3%)
Oxycodone (5 mg oral)	1 (3%)	0
Fentanyl	7 (25%)	1 (3%)
Cumulative dose of PACU opioids [in Morphine Milligram Equivalents (MMEs)]	**Mean = 2.46 ± 2.62 95% CI (1.44 – 3.47)**	**Mean = 1.60 ± 2.68 95% CI (0.58 – 2.62)**
0	7 (25%)	17 (59%)
0.1 – 0.9	5 (18%)	1 (3%)
1 – 1.9	2 (7%)	2 (7%)
2 – 2.9	6 (21%)	2 (7%)
3 – 3.9	1 (3%)	0
4 – 4.9	1 (3%)	1 (3%)
5 – 5.9	2 (7%)	2 (7%)
6 – 6.9	3 (11%)	1 (3%)
7 – 7.9	0	1 (3%)
8 – 8.9	0	0
9 – 9.2	1(4%)	1 (3%)
48-hour pain scores	**Mean = 4.21 ± 2.54 95% CI (3.23 – 5.20)**	**Mean = 1.9 ± 1.88 95% CI (1.18 – 2.61)**
0	0	8 (28%)
1 - 2	10 (36%)	11 (38%)
3 - 4	6 (21%)	9 (31%)
5 - 6	7 (25%)	0
7 – 8	3 (11%)	1 (3%)
9 - 10	2 (7%)	0

Variable	Self-administered Opioids from Time of Discharge through 48 Hours after Discharge (N=28)	No Opioid Use from Time of Discharge through 48 Hours after Discharge (N=29)
48-hour opioid drug type		**0**
Hydrocodone bitartrate + acetaminophen 325 mg (Norco®)	14 (50%)	
Hydrocodone bitartrate + acetaminophen 300 mg (Vicodin®)	1 (3%)	
Oxycodone (OxyIR®) 5 mg	5 (18%)	
Tramadol hydrochloride (Ultram®) 50 mg	6 (21%)	
Oxycodone 5 mg + acetaminophen 325 mg (Percocet®)	2 (7.1%)	
# of opioid tablets taken at 48 hours	**Mean = 9.52 ± 15.46** **95% CI (5.42 – 13.62)**	**0**
1 - 2	15 (52%)	
3 - 4	4 (14%)	
5 - 6	3 (11%)	
7 - 8	2 (7%)	
9 - 10	4 (14%)	
MME of opioid tablets taken at 48 hours	**Mean = 9.52 ± 15.46** **95% CI (5.42 – 13.62)**	**0**
5 mg	10 (35.7%)	
7.5 mg	2 (7.1%)	
10 mg	2 (7.1%)	
15 mg	3 (10.7%)	
20 mg	2 (7.1%)	
25 mg	2 (7.1%)	
30 mg	1 (3.6%)	
40 mg	1 (3.6%)	
50 mg	4 (14.3%)	
52.5 mg	1 (3.6%)	

4.5.2 Demographic characteristics

The average participant was 71.89 years old, with age 72 being the most common age in this cohort of older women, representing 17.5% of the sample. The majority of the sample was White/Caucasian (91.2%)—four participants (7%) were Black/African American. No other ethnicities were included in the analysis.

4.5.3 Surgical characteristics

At 64.9% (n=30), the majority of women included in this study did not receive any preoperative medications. Of the 26 women who were premedicated, seven (27%) received acetaminophen (Tylenol®) by mouth, and seven (27%) received acetaminophen in combination with other medications. A unilateral segmental mastectomy was the most commonly performed surgical procedure on this cohort of women, with 64.9% (n=26) undergoing either a right or left-sided segmental mastectomy. The most commonly administered anesthetic agent for this cohort was sevoflurane (n=34, or 59.6% of participants).

4.5.4 PACU characteristics

The mean combined pain scores while in the PACU was 2.98 out of a possible "10" with "0" being the most commonly reported average score (26.3%). Average pain scores ranged from zero to 7.5 on the NRS. The number of women who did not receive any opioid analgesia while in the PACU totaled 24 out of 57 (42.1%). Of patients receiving analgesics, the average cumulative morphine equivalent received was 2.02 mg. Dilaudid® (hydromorphone) was the most frequently

administered agent, with 19 of the 25 women who required opioid analgesia during their PACU stay (76%) receiving at least one dose of hydromorphone. A total of eight participants (14%) received Sublimaze® (fentanyl) either as a single agent or in combination with another opioid.

4.5.5 48-hour post-discharge characteristics

The mean post-discharge pain score among this cohort of older women was 3.04 with "2" being the most commonly reported (19.3%). At this timepoint, eight study participants (14%) reported no pain, and 29 (51%) required no opioid analgesia post-discharge. Table 4 lists responses study participants provided as rationale for not requiring opioid analgesia.

Table 4. Verbal responses for not taking prescribed opioid analgesia after discharge

Reason Given for Not Taking Prescribed Opioid Analgesia after Discharge	Age
"Vicodin n'at upsets my stomach—ice packs controlled my pain well enough."	72
"No, I did not fill the prescription. My pain was never bad enough that I thought it was necessary."	71
"I never needed any pain medication and did not take any Tylenol. I feel very fortunate. It may be hard to believe, but I did not experience any pain following surgery."	65
"I did not take (it) because I had it before, and it made me nauseated. My pain was adequately controlled with over-the-counter meds."	67
"I didn't need any pain medicine—I didn't even bother to fill the prescription. Surgery was a breeze."	72
"I got a written prescription, but they never brought me an actual bottle of tablets. I ended up not needing it filled because it was not needed. My pain was relieved by ibuprofen."	68
"I did fine with ibuprofen at home but had horrible pain in recovery room. Two doses of IV Toradol didn't touch it—they had to control it with morphine. I took ibuprofen that night, maybe the next day--I took my prescription home, but I didn't need it."	69
"I did not fill the prescription. I had a history of using pain medication to help with a broken rib, and it took longer than I expected to get off the tablets. I also slept in a recliner for part of the night for about a month. This time, I used Extra Strength Tylenol for pain instead."	68
"I took my script home but didn't fill it. I have a high pain tolerance. Tylenol took care of my pain. I guess I'm paranoid. I don't take anything since I had codeine for my cough when I was in college 50 years ago and didn't like the way it made me feel. After that, I would go to parties and make sure I covered my drinks. After that, I wouldn't even take aspirin! I took extra strength Tylenol, no more than 2000 mg/day and used heating pads. Prayers help me feel better."	71
"Breast surgery is really not that painful—I can't remember if they brought me my tablets to take home or not, but I didn't need it. My appendectomy was more painful that any of my three breast surgeries."	72

Reason Given for Not Taking Prescribed Opioid Analgesia after Discharge	Age
"I got my prescriptions for Norco filled but did not take them because I really didn't experience pain at the time of my surgeries. I keep them around to take when I really want them but try to avoid them because they are not good for my constipation."	76
"I took Tylenol one time. I filled my prescription, but I just never needed it."	77
"I never filled my prescription because I really had very minimal pain and only the day after my surgery. Since I had a son in law who died of a drug overdose, I am extremely reluctant to use prescription pain drugs of any sort. Also, since I had both a knee and hip replacement, and both were very much more painful than my breast surgery, my pain would have to have been MUCH more extreme to even consider a prescription pain med. My breast pain never reached the level at which I would have requested a prescription drug. I may have taken Arthritis Strength Tylenol 1-2 times for my breast pain. Ordinarily, since I still have moderate pain due to arthritis in my knees and hips, I usually have taken Tylenol for the day before any breast pain would develop."	69
"I didn't need it, so they didn't prescribe any for me. My first day, I took Tylenol because I was sore. I used ice after my biopsies and was told to avoid heat."	74
"I didn't take any pain medicine because I never needed it. I didn't take the prescription offered to me because I didn't have any pain."	70
"I filled a prescription for 10 Lortab-5s, but I did not use them. I'm not a pill popper! I got it filled just in case. My pain was relieved by Tylenol."	69
"I did not fill the prescription because I did not need it. I only had minimal pain, mostly discomfort."	72
I got my prescription filled but didn't take it. My pain is mostly related to my knees, for which I use CBD oil. I am taking Tylenol 1000 mg every 6 hours around the clock to keep this pain manageable."	72

Of those who employed opioid pain relief (49%, n=28), nearly half self-administered only one tablet of their prescribed opioids. As illustrated in Table 1, the remaining 16 of 28 women self-administered between two and 10 opioid tablets each. Norco® (hydrocodone bitartrate 5 mg combined with acetaminophen 325 mg) was most frequently prescribed, and 14 of the 28 women requiring prescription opioids reported taking Norco®. Of these 28 study participants requiring opioid analgesia, six self-administered Ultram® (tramadol) following surgery; however, nearly half of these women also employed tramadol for the relief of pain caused by chronic conditions such as osteoarthritis prior to breast surgery and continued to do so postoperatively. Figure 3 categorizes the opioid dosages self-administered during the 48-hour post-discharge period and the percentages of these 28 women in each dosage category.

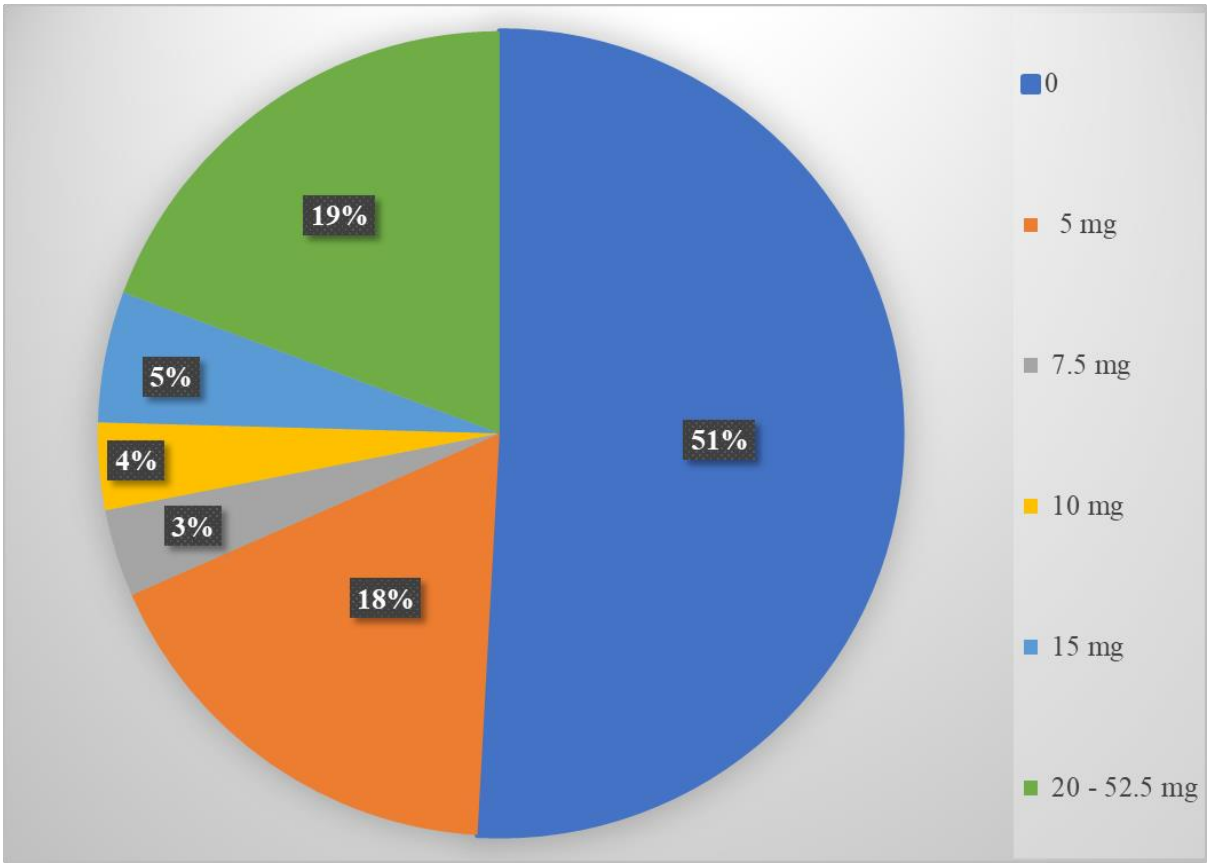

Figure 3. Opioid dosages and the percentages of participants taking each during the 48-hour post-discharge period following breast cancer surgery

4.5.6 Associations among factors for opioid use within 48 hours post-discharge

Regression modeling revealed, at α=0.05, that *48-Hour Opioid Drug Type* (B=0.900, SE=0.220, $p<0.001$, semi-partial $r^2=0.219$) and *PACU Opioid Type* (B=0.508, SE=0.215, $p=0.022$, semi-partial $r^2=0.073$) significantly predicted *MME of Opioid Tablets Taken at 48 Hours*. None of the other variables employed in this secondary analysis were significant predictors of the amount of opioid analgesia study participants required to control their postoperative pain during the 48-hour period after discharge. Table 5 represents correlations among the continuous variables employed in this analysis.

Table 5. Correlations among continuous variables included in the analysis

		Age	Mean Post-operative Pain Scores	Cumulative Dose of Post-Anesthesia Care Unit (PACU) Opioids***	48-Hour Pain Scores	Cumulative Dose of Opioid Tablets Taken at 48 Hours***
Age	Pearson Correlation	1	-0.177	-0.134	-0.156	-0.010
	Sig. (2-tailed)	--	0.188	0.319	0.248	0.943
Mean Post-Operative Pain Scores	Pearson Correlation	-0.177	1	.724**	.368**	.349**
	Sig. (2-tailed)	0.188	--	**<0.001**	**0.005**	**0.008**
Cumulative Dose of Post-Anesthesia Care Unit (PACU) Opioids* **	Pearson Correlation	-0.134	.724**	1	.339**	.280*
	Sig. (2-tailed)	0.319	**<0.001**	--	**0.010**	**0.035**
48-Hour Pain Score	Pearson Correlation	-0.156	.368**	.339**	1	.418**
	Sig. (2-tailed)	0.248	**0.005**	**0.010**	--	**0.001**
Cumulative Dose of Opioid Tablets Taken at 48 Hours* **	Pearson Correlation	-0.010	.349**	.280*	.418**	1
	Sig. (2-tailed)	0.943	**0.008**	**0.035**	**0.001**	--

4.6 Discussion

The main finding of this study was that the majority of older women in this cohort (29 out of 57, or 51%) did not experience pain severe enough to warrant high dosages of opioid analgesia following their respective early-stage breast cancer surgeries. This is reflected in the low overall mean PACU pain scores in this cohort of only 2.98 out of 10; the average dosage of opi-

oid analgesia received in the PACU of only 2.02 MMEs; and the mean dosage of 9.52 MMEs taken 48 hours after discharge from PACU. Because the quality and quantity of postoperative breast surgery pain is dependent upon the procedure performed (Murphy et al., 2019), the low overall pain scores and amount of morphine equivalents required may be attributed to the high number of women in this sample who underwent segmental mastectomies (n=41), which are considered less invasive than total mastectomies. The two factors our analysis revealed as having significant effects on the amount of opioid analgesia required were *PACU Opioid Type* and *48-Hour Opioid Drug Type*. This finding may indicate that the type of opioid analgesia administered both in PACU and while recovering at home predicts the amount of analgesia required by patients recovering from breast cancer surgery following discharge from the hospital. However, more extensive research comparing patients' responses to different combinations of analgesia is needed to confirm this finding.

Table 4 lists verbal responses given by some of these older study participants when asked to explain their reasons for choosing not to fill their opioid pain medication prescription post-discharge. While responses varied, two of these study participants mentioned that they followed the post-discharge instruction to apply ice to the surgical wound, and this decreased their pain sufficiently. Another 11 of the respondents mentioned managing their postoperative pain with over-the-counter preparations, such as acetaminophen (Tylenol®) and ibuprofen (Motrin®). This finding is consistent with studies involving both older adults and patients with breast cancer. A study of older adults conducted by Fowler et al. (2014) concluded that the number of non-steroidal anti-inflammatory drugs (NSAIDs) older adults utilize is three times higher than the amount younger adults reportedly use. In a study of women newly diagnosed with breast cancer after primary surgery for breast cancer, Fenlon et al. (2014) discovered that 49% of women who

underwent surgery for breast cancer in the prior 30-day period advocated pain relief from over-the-counter analgesia. In a study of women aged 18 through 85 who were experiencing pain at least three months following breast cancer surgery, Beyaz et al. (2016) found that 59.5% controlled their pain with anti-inflammatory medications and/or simple analgesics.

As Table 5 demonstrates, at α=0.05, significant relationships were revealed between mean postoperative pain scores and cumulative postoperative opioid dosages (p<0.001); 48-hour pain scores (p=0.005); and 48-hour opioid dosages (p=0.008) and between 48-hour opioid dosages and cumulative postoperative opioid dosages (p=0.035) as well as 48-hour pain scores (p=0.001). Future analyses exploring the relationships among these variables would inform optimal pain management during the recovery periods immediately following breast surgery and following discharge to home/self-care.

4.6.1 Women who did not require post-discharge opioid analgesia

Several differences were noted between study participants requiring postoperative opioid analgesia and those who did not. Of the 29 women in this group, 17 (58.6%) did not require opioids in the PACU or during the 48-hour post-discharge period. We expected to find that the 29 women who did not take post-discharge opioids did so because of their fear of addiction, stigma, and/or adverse effects, including nausea, constipation, and somnolence. However, only one woman in this group endorsed a pain score over 4/10 during her 48-hour post-discharge telephone follow up, explaining that she was just “pretty sore” and did not fill her opioid prescription because she did not need it. Of the five next highest scorers in this group (all reported 4/10 pain), one of the women relayed that she did not need opioid analgesia post-discharge because

her pain was managed so well in the PACU. A total of 13 of these 29 women actually filled their opioid prescriptions yet reported that the prescription proved unnecessary.

4.6.2 Findings among all study participants

The overall low pain scores and low dosages of opioid analgesics required for postoperative and post-discharge pain control in this population can be attributed to a number of factors. All data were collected in the same surgery centers with consistently the same surgical team who follow the same Enhanced Recovery after Surgery (ERAS) protocols. This not only provided for reliability in data collection but also served to optimize postsurgical outcomes for the participants included in this secondary analysis.

The pain experiences of older women with breast cancer during the immediate postoperative period following breast cancer surgery and again at 48 hours postoperatively were the primary focus of the present study. As multiple physiologic processes are affected by aging, older adults often experience slowed metabolism, lower distribution volumes, and higher end-organ sensitivity to anesthetic agents (Akhtar & Ramani, 2015). Thus, the 48-hour recovery period following discharge may have been inadequate to allow for older women to fully process anesthetics and other agents received during the perioperative period, resulting in lower postoperative pain scores. For example, a study by Divella et al. (2020) found that 105 of 261 women with breast cancer (48.2%) endorsed chronic pain six months following breast surgery. Because the parent study follows women with breast cancer longitudinally over the course of one year and is currently offering the opportunity for continued participation for two additional years, future studies of the pain experiences of these women across longer periods of time will be possible.

Impaired ability to metabolize anesthetic agents renders regional anesthesia an ideal consideration for older adults, as it decreases physiologic stress on patients whose physiologic reserves are already limited. Multimodal approaches to perioperative pain management that included the use of regional anesthesia have been proven to decrease opioid use and pain scores as well as improve postoperative functionality and patient satisfaction (Lin et al., 2019). While the surgical staff involved in this study do occasionally employ regional anesthesia when performing breast surgeries, none of the patients included in this secondary analysis received regional anesthesia. Future studies that compare postoperative pain levels and functionality in older adults between those who received systemic versus regional anesthesia would inform best perioperative practices for this population.

Even among the group of 28 women who did require postoperative analgesia either while in the PACU or post-discharge, opioid usage was minimal. Seven of these 28 women (25%) did not require analgesia while in the PACU, and of those who did, the average dose administered was less than 2.5 MMEs. 54% (n=15) of study participants requiring opioid analgesia post-discharge used only one or two of their prescribed opioid analgesic tablets—12 participants only required one, and three reported self-administering two tablets. Variability among opioid analgesic type was also low. Of the 21 out of 28 women in this group who required opioid analgesia in the PACU, 11 (39%) received hydromorphone alone--14 (50%) of these 28 women who required post-discharge opioid analgesics received Norco® (hydrocodone bitartrate 5 mg combined with acetaminophen 325 mg).

4.7 Limitations

Both the parent study and this secondary analysis are nonexperimental, inherently limiting this study's generalizability. The small overall sample size of 57 women and the fact that only 28 of these women required opioid analgesia post-discharge also contribute to the limited ability to apply this secondary study to the general population.

Although the surgical teams at both facilities included in the parent study adhere to ERAS protocols to optimize patients' surgical outcomes, their practices may differ from other surgical groups. This may have influenced the outcomes and therefore limited generalizability to other surgery centers. The variables *48-Hour Opioid Drug Type, Number of Opioid Tablets Taken at 48 Hours,* and *48-Hour Pain Scores* relied on patient self-report and ability to recall facts during an often fast-paced and stressful period of study participants' lives—thus, recall bias may have also impacted the results.

Study participants were not asked to distinguish whether the opioid pain medications they self-administered during the 48-hour period post-discharge were intended for relief of acute, postoperative pain or to alleviate pain from a chronic condition such as osteoarthritis. Another limitation of this secondary analysis was its exploration of older women's pain experiences retrospectively, relying largely on participants' ability to recall and self-report their perceptions of the pain at the time it occurred.

4.8 Future studies

Recruitment continues for the parent study, which examines cancer-related symptoms that adult women with breast cancer experience during their recovery period after breast surgery to three years out from surgery. This will enable the collection of extensive symptom-related data, including pain experiences, for this age group, providing data for more secondary analyses specific to women in this cohort who are age 65 or older. A study employing qualitative interviews with select participants from the parent study who are age 65 and older to discuss their unique pain experiences will be conducted in the coming months. This will provide opportunities for this distinctive age group to discuss their personal perspectives on pain and pain management.

Our analysis revealed that *48-Hour Opioid Drug Type* and *PACU Opioid Type* were the only two factors significantly associated with the dosage of opioid analgesia study participants required 48 hours post-discharge. Therefore, research addressing distinct types of preoperative medications, surgical procedures, anesthetic methods, and medications (both opioid and non-opioid) that optimize perioperative pain management should be the focus of future studies employing a larger sample of women following breast cancer surgery.

In this secondary analysis, we found that 12 of 57 older participants filled but did not use their prescribed opioid analgesics while another 12 only required one tablet. These data elucidate the need for more research regarding the importance of providing education to this patient population about pain management practices, particularly safe use and handling of opioids. This should include instructing the patient and caregiver about safe disposal of unused opioids, in the event that the patient does not require all the opioid tablets prescribed for them. The website for the Diversion Control Division of the Drug Enforcement Agency (DEA) contains a search capa-

bility by postal code for drug take back locations within a five to 50-mile radius. Ensuring this website and information on the dangers of failing to properly dispose of unused opioids are included in patient discharge instructions will decrease the likelihood of diversion or being flushed down the toilet and infiltrating water supplies.

As previously mentioned, older adults tend to downplay and undertreat their pain. Therefore, evidence supporting the critical need for educating patients with cancer to notify clinicians immediately at the onset of acute pain or inability to control chronic pain should be a research priority. This education should include information regarding who to call when this pain remains unrelieved after enacting interventions or if the quantity of analgesia on hand to manage their pain is insufficient.

Nurses play a key role in assisting clinicians with optimization of the amount and type of pain medication prescribed. Conversations with patients during preoperative teaching regarding pain management practices are absolutely vital. More research that provides guidance for nurses and clinicians with the challenges associated with balancing adequate postoperative pain control with prescribing the appropriate type and amount of oral analgesics for patients to take at home could mitigate this problem.

Research supporting the importance of preoperative discussions with older adult patients involving their medical and medication histories, including the reasons any medications were discontinued; tolerance and efficacy of pain medications they have taken in the past; and current analgesic practices for conditions such as osteoarthritis that are common in this patient population will facilitate the prescription of postoperative pain management plans that are both safe and efficacious. For example, older adults with liver failure will require restricted use of acetaminophen and opioids, while those with kidney failure may need to avoid or limit the use of NSAIDs,

including Toradol® (ketorolac), for pain relief. Gathering complete medication and pain histories will also decrease the likelihood that duplicate medications or medications in the same drug class will be prescribed and aid in preventing possible adverse effects of opioid analgesia, including accidental opioid overdose. This research should also highlight that provision of thorough patient education regarding postoperative pain management empowers older adults with cancer to adequately manage their pain, resulting in maximum quality of life and decreased development of debility.

Studies that reflect the efficacy of nurse-led protocol development of pain interventions among their perioperative care teams will promote consistency in pain control practices for older adults. These protocols should accommodate patients for whom standardized pain management protocols would be dangerous. For example, if a patient will resume prescribed anticoagulant therapy after discharge and is going home with surgical drains in place, it may be prudent to avoid postoperative use of NSAIDs to decrease the likelihood of postsurgical bleeding.

4.9 Conclusions

Among all the characteristics explored in this secondary analysis, only the type of opioids received while in the PACU and 48 hours after discharge emerged as being associated with the amount of opioid analgesia required by older women following discharge after breast cancer surgery. This study demonstrated that postoperative pain was generally well-controlled in this sample of older women during their PACU stay and 48 hours following discharge. More than half of the women involved in this study chose not to employ opioid analgesia to manage post-operative pain. Future studies that explore the reasons older women choose not to employ opioid analgesia

for pain management and the factors that contribute to optimal pain management will improve quality of life for older women with breast cancer from diagnosis through survivorship to end-of-life care.

5.0 Qualitative manuscript (Aim 1): Optimizing pain management for women aged 65 and older with breast cancer: Challenges and opportunities

Presented here is the full-text version of the manuscript submitted for publication to the *Oncology Nursing Forum*.

5.1 Abstract

Purpose: Despite evidence-based guidelines for managing pain, women treated for breast cancer continue to endorse pain throughout their cancer care trajectories. To gain a better understanding of this finding, the aim of this study was to explore the experiences and factors influencing pain management among women aged 65 and older who reported moderate to severe pain within the first year after breast cancer surgery.

Participants and Setting: A subsample of 21 women aged > 65 years enrolled in a larger parent study who endorsed at least one experience of moderate to severe pain. Multiple sampling techniques were used to recruit participants representing varied pain experiences and racial minorities.

Methodologic Approach: The study employed qualitative description and thematic analysis of one-on-one, semi-structured interviews to identify evolving themes and overarching categories.

Findings: Three categories emerged: facilitators of optimal pain management, challenges to optimal pain management, and other factors affecting optimal pain management.

Implications for Nursing: Empowering women aged 65 and older treated for breast cancer to optimally manage pain by facilitating open communication with the care team, establishing a pain management plan, and providing information about analgesia and other pain management strategies will improve pain outcomes and overall quality of life.

Knowledge Translation:

- Women treated for breast cancer who are aged 65 and older reported several strategies for nurses to optimize pain management, including fostering empathetic and open communication between patients and members of the healthcare team, collaborating with patients

and their cancer care providers to facilitate the use of evidence-based guidelines to create individualized pain management plans, and educating patients regarding proper utilization of analgesics and other pain management modalities.

- Women aged 65 and older treated for breast cancer reported challenges to optimal pain management including ineffective care team interactions resulting in fragmented care, insufficient information regarding analgesia and other pain-relieving measures, negative attitudes such as opioid stigma impairing forthright clinical conversations regarding pain, and factors associated with undermanaged pain including the psychological influences of hopelessness and depression and physical influences of chronic comorbid painful conditions.
- As the number of women aged 65 and older diagnosed with breast cancer continues to increase, future research focused on strategies to facilitate optimal pain management and combat the unique challenges encountered by this population when pain is undermanaged becomes increasingly vital to improving overall functioning and quality of life.

5.2 Background

Breast cancer is the most common type of cancer, occurring most frequently in women over 65 years of age, regardless of race and stage (SEER, 2022). Despite multiple evidence-based strategies for mitigating cancer pain (see Figure 4 for summary of literature), nearly half of patients with cancer report undermanaged pain (Krishnamani et al., 2022). Studies involving patients with breast cancer reflect this finding with percentages between 25 and 71.7% throughout the cancer care trajectory (Costa et al., 2017; Divella et al., 2020; Wang et al., 2018). A paucity

of pain research unique to the experiences of women (Keogh, 2022) and adults with cancer who are aged 65 and older exists, despite bearing the highest risk for cancer (Haase et al., 2021). The prevalence of breast cancer among women aged 65 and older and their frequent accounts of undermanaged pain led us to focus our research on a cohort of women aged 65 and older treated for breast cancer. Thus, the purpose of this study was to explore experiences and factors regarding pain management from the perspectives of women aged 65 and older reporting moderate to severe pain within a year after breast cancer surgery to gain insights about better pain management.

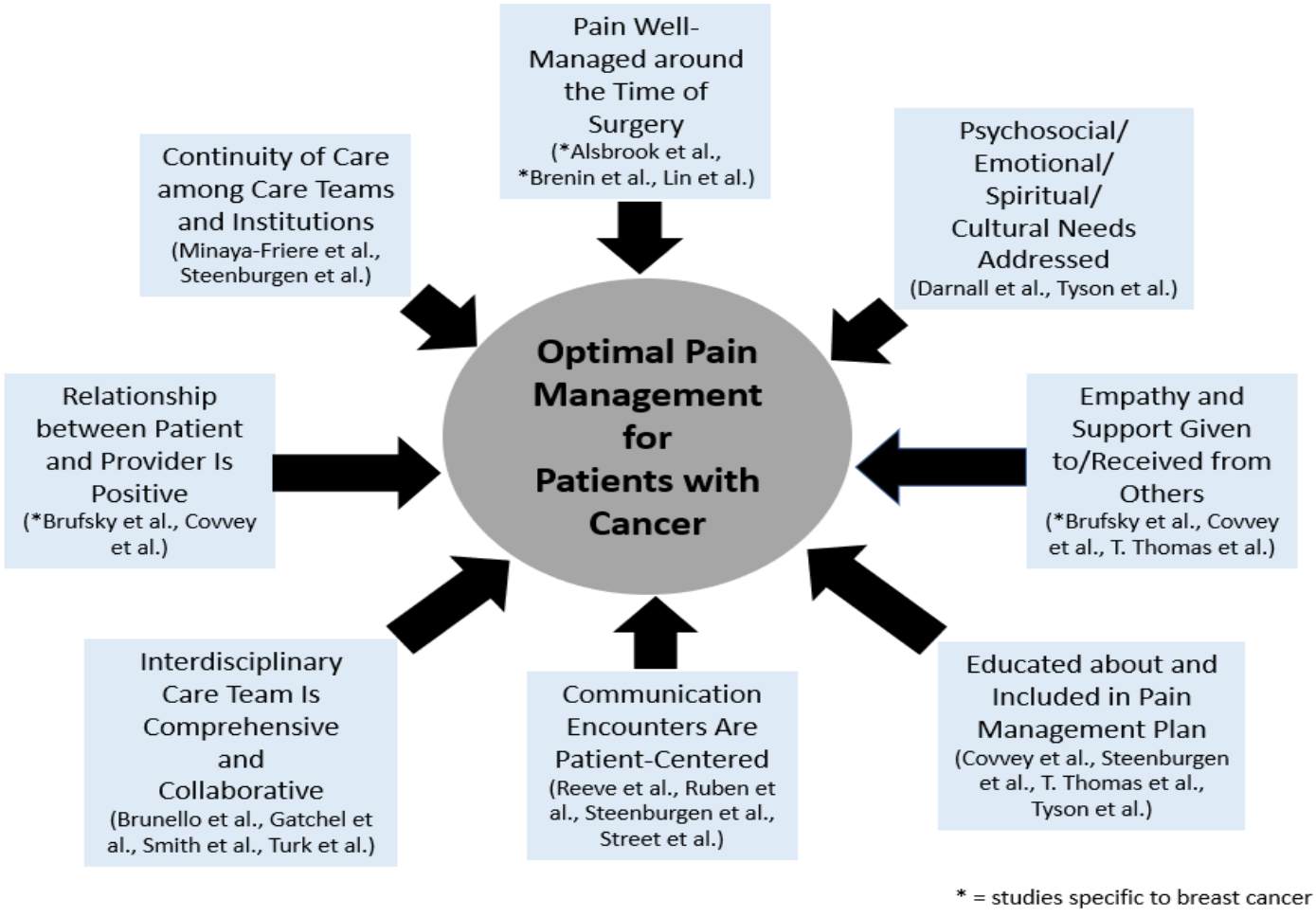

Figure 4. Summary of strategies for optimizing pain management for patients with cancer found in the literature

5.3 Methods

5.3.1 Design, setting, and sample

5.3.1.1 Design and setting

We employed qualitative description, a qualitative research methodology conducive to studying research phenomena free from preconceived classification and producing findings closely aligned with the collected data (Sandelowski, 2000, 2010). Study participants were recruited from a cohort of women with breast cancer enrolled in a large, longitudinal study (N=356) entitled "Genomic Underpinnings for Breast Cancer Treatment-Induced Nausea and Vomiting" (NR016695, S. Wesmiller, PI). Accrual for the parent study occurred at two hospitals within the University of Pittsburgh Medical Center (UPMC): Magee Womens Hospital and UPMC East. Both hospitals are affiliated with the UPMC Hillman Cancer Center Comprehensive Breast Care Program. Inclusion criteria for the parent study required participant age of 18 to 90 years; diagnosis of early-stage breast cancer defined as American Joint Committee on Cancer staging criteria classification (7th edition) stage I, II, or IIIa (Edge et al., 2010); no clinical evidence of distant metastases; scheduled for breast surgery anticipated to last 4 hours or less; and no history of neurologic conditions, including stroke, head injury, spinal cord injury, and intracerebral hemorrhage.

5.3.1.2 Recruitment and sampling

After University of Pittsburgh Human Research Protection Office approval, recruitment began in March 2021 and ended in June 2021. We approached study participants by their preferred method during the parent study (email or telephone). Credible, reliable sampling in quali-

tative research is achieved by selecting participants who can provide information-rich responses about the phenomenon of interest (Patton, 2015). To optimize the richness and representativeness of participant responses, we first employed criterion sampling (Creswell & Poth, 2018b) to identify women who were ≥ 65 years of age and reported pain at a level of "4" or above, a clinically meaningful cut-off point on the 0-10 Numerical Rating Scale (NRS) for moderate pain interfering with functioning (Boonstra et al., 2016), anytime during parent study participation. Applying these criteria maximized homogeneity (Dicicco-Bloom & Crabtree, 2006) of the sample (n=74). Secondly, we purposefully sampled all women of color (n=8) to increase racial diversity (Creswell & Poth, 2018b; Sandelowski, 1995). Thirdly, we applied reputational case selection (Miles & Huberman, 1994) to the remaining eligible individuals (n=66) to identify: 1) those most active in the parent study, and 2) those considered by research associates to illustrate various pain management experiences to ensure findings adequately represented the target population.

Based on this sampling plan, we identified 35 individuals to approach with the goal of completing three interviews per week. Eight were unreachable; three declined to enroll (reasons included participation would take too long, recent surgery, and complications from existing health problems); and three withdrew prior to being interviewed (reasons included complications of treatment for liver metastases, a spouse's acute critical illness, and refusal to audio-record the interview). Those agreeing to participate were scheduled for a telephone interview and received a reminder letter for the interview appointment and copy of the consent form to review prior to verbally consenting immediately before the interview. Recruitment continued until the team agreed that data saturation, the point at which no new codes emerged from the interview transcripts (Creswell & Poth, 2018a) had been achieved, resulting in a final sample of N=21, meeting

the recommendation for sample sizes between 3 and 20 for qualitative descriptive studies (Magilvy & Thomas, 2009).

5.3.2 Procedure and data collection

5.3.2.1 Interview process

A semi-structured interview guide (Creswell & Poth, 2018c) was developed to gather participants' descriptions of lifetime experiences of pain; care team communications regarding pain management, particularly when having experienced changes in pain status; attitudes regarding opioid pain management; and obstacles encountered in obtaining resources pertinent to pain management. We employed several strategies to increase the interview guide's content validity, clarity, and probative value including an initial review by a breast cancer survivor over the age of 65 who was also an experienced nurse practitioner and non-participant in either the parent or the present study; a mock interview with another non-participating woman with breast cancer over the age of 65; and finally, a review of the first three interview transcripts by an expert in qualitative methodologies (A.D.D.) who made recommendations to improve the quality of responses and interview techniques. The final iteration of the interview guide is shown in Table 1.

Of the 21 interviews performed, C.H. conducted one, S.P. conducted two, and K.A. conducted the remaining 18. All were trained in qualitative data collection procedures, including one-on-one interviewing; discussing sensitive topics; and ensuring qualitative rigor using the strategies for trustworthiness of qualitative research (Lincoln & Guba, 1985). To ensure privacy, interviews were conducted via telephone from the interviewers' homes.

Before each interview, the interviewer obtained informed consent and permission to record. Each interview lasted between 6 and 60 minutes. Interviewers saved recordings on personal,

password-protected laptops. The "Dictate" feature in Microsoft Word® was used to generate transcripts. Each interviewer reviewed the audio recording and verified the transcripts for accuracy. Transcripts and recordings were then transferred to a secure network drive maintained by the School of Nursing.

Table 6. Final version of interview guide (questions are numbered with probes under each)

Interview Questions
1. (Participant's First Name), can you please tell me what all you have done and are doing to manage your pain? a) Do you take prescribed pain medications? b) Do you take anything over the counter for pain? c) Do you ever apply ice/heat/pain-relieving cream?
2. How well do these treatments work? a) Does the pain get better/worse? b) Does it relieve the pain/make it manageable?
3. Do you remember if or how you were instructed or otherwise prepared to take this medication (or perform this intervention, such as application of ice/heat) and the directions you were given? a) When you were sent home after your surgery, for example, how were instructions for relieving your pain given to you?)
4. Can you tell me about a time your pain was not well-managed? a) If you don't take medications to relieve your pain, what do you do to cope with the pain?

Interview Questions
b) What difficulties have you experienced associated with pain?
5. What are your thoughts about using opioid pain medications like tramadol, hydrocodone, oxycodone, Dilaudid, codeine, and morphine to manage pain?
6. Do you have a team of doctors, nurses, nurse practitioners, physician assistants responsible for your cancer care? a) **If yes: "Tell me about your relationship with your cancer care team."** b) **If no: "When your pain is not well-controlled, who do you notify?" Then, refer to this person/persons instead of "cancer team/care team," moving forward.**
7. Tell me about how you and your care team work together to plan for keeping your pain well-controlled. a) What have you and your cancer team decided to do when you have pain?)
8. How would you describe your cancer team's responsiveness to your pain needs? a) Describe any problems you have encountered with your cancer team regarding pain.
9. Is there anything else you feel I should know about pain and your cancer team?

5.3.3 Data analyses

Transcripts were uploaded to NVivo® Version 12 Qualitative Data Analysis (QDA) software (released in March 2020). Four coders (K.A., C.H., S.P., and E.K.) applied open coding such that codes were emergent rather than prefigured (Creswell & Poth, 2018a). After every third interview, the team met via videoconference to discuss the coded transcripts and apply constant comparative analysis (American Psychological Association, 2020), an iterative process of reduc-

ing the data by comparing codes across all interviews (Glaser & Strauss, 1967) to identify participants' significant statements and patterns to incorporate into the evolving codebook. Coding disagreements were resolved through discussion until achieving consensus. Team members applied each iteration of the codebook to additional transcripts incorporating new codes into all transcripts. Meeting minutes were reviewed after each meeting by K.A. to ensure process validity and rigor. Team members repeated these steps until agreeing that data saturation, the point in data collection when no additional issues or insights were identified (Sandelowski, 1995), was reached after coding and discussing the 21st transcript and ended recruitment. Participants received "thank you" notes and $25.

K.A. performed the final steps of analysis in consultation with A.D.D. All coded transcripts were reviewed and recoded as necessary based on the final version of the codebook. Thematic analysis was performed by collapsing related codes under themes, then identifying the categories around which themes clustered (Braun and Clarke, 2006, 2012). For reporting purposes, we calculated the percentage of participants whose responses were coded under each theme.

5.3.4 Strategies for enhancing trustworthiness

We followed recommendations for rigor of qualitative studies (Lincoln & Guba, 1985; Thomas & Magilvy, 2011). To enhance credibility, we reviewed transcripts for commonalities among study participants and used participants' own words when possible in reporting our findings. We demonstrated transferability by fully describing sample factors such as age, race, ethnicity, and surgery types. To meet dependability criteria, we clearly stated the study's purpose; provided a detailed outline of the participant selection process; described the interviewing and data collection processes; and explained the results and supported them with findings from the

literature. Examples of confirmability include our audit trail documenting researchers' self-reflective attitudes; perceptions and biases experienced before, during, and after each interview in memos; and minutes of weekly analysis meetings (Creswell & Poth, 2018a).

5.4 Findings

5.4.1 Sample characteristics

The mean age of participants in this subsample (N=21) ranged between 65-84 years (Mean=73.24 ± 5.21). On average, interviews were conducted 1.79 years after initial breast cancer surgery. By the time of the interview, 18 patients completed parent study participation, and an average of 0.96 years elapsed between parent study completion and participant interviews. Other characteristics of the sample are presented in Table 7.

Three overarching categories emerged from the thematic analysis: facilitators of, challenges to, and other factors affecting optimal pain management. Figures follow the findings below and contain exemplary quotations coded to each category.

Table 7. Sample characteristics (N=21)

Characteristic	**n (%)**
Age (years)	
65-70	8 (38.1%)
71-80	10 (47.6%)
81 or older	3 (14.3%)

Characteristic	**n (%)**
Race and Ethnicity	
Black/African American (non-Hispanic)	7 (33.3%)
White/Caucasian (non-Hispanic)	14 (66.7%)
Number of Years between Initial Breast Surgery and Participation in Present Study	
Less than 1 year	3 (14.3%)
1-1.99 years	8 (38.1%)
2-2.56 years	10 (47.6%)
Surgery Type	
Unilateral segmental mastectomy	18 (85.7%)
Bilateral segmental mastectomy	1 (4.8%)
Unilateral total mastectomy	2 (9.5%)
Bilateral total mastectomy	0
Adjuvant Treatment Received	
Chemotherapy + radiation	3 (14.3%)
Radiation + aromatase inhibitor	14 (66.7%)
Aromatase inhibitor only	4 (19.0%)

5.4.2 Facilitators of optimal pain management

The seven themes and exemplary quotations in this category are shown in Figure 5. The majority of participants (n=14, 67%) reported at least one patient-centered communication interaction regarding pain management. Participants described care teams as responsive and receptive to questions and concerns, attentive, caring, and creating an atmosphere conducive to open and honest communication about pain and its management.

Participants also endorsed pain management information and/or education (n=15, 71%) as beneficial. For example, one participant acknowledged receiving pain management instructions upon discharge home from surgery and also received information regarding pain as an adverse effect of treatment, empowering her to notify the care team who promptly intervened to mitigate the pain.

Among interview participants, 43% (n=9) regarded opioid analgesia as an effective means of pain management and/or endorsed successfully managing pain with opioids. Even more frequently, participants reported willingness to employ complementary pain management modalities (n=17, 81%). Participants listed multiple methodologies in conjunction with or instead of oral analgesics for managing pain, including application of ice, heat, or topical analgesics (e.g., patches and gels containing lidocaine) and involving non-medical personnel (e.g., alternative healers, massage therapists).

Of those participants who recalled pain management experiences around their breast surgeries, 43% (n=9) perceived their pain to be well-managed immediately following surgery and post-discharge. Often, participants required little or no opioid analgesia or mitigated pain by following postoperative instructions (e.g., performed prescribed exercises, wore a support bra, adhered to activity restrictions). 24% (n=5) attributed successful pain management to proactively

preventing pain from becoming undermanaged. Some participants recalled employing analgesics to “stay ahead” of their pain around the time of breast cancer surgery.

Participants frequently endorsed reliance on psychosocial assets (n=17, 81%) to optimize pain management. These included self-described high tolerance for pain, positive attitude, and ability to provide support to and receive support from others regarding pain management.

PATIENT-CENTERED COMMUNICATION REGARDING PAIN (n=14, 67%)

- "They've always made me feel comfortable about discussing my pain, and they make suggestions if the pain persists."
- "They were all, they were just great! They would always ask, you know, was I having any pain, or any concerns. And I'm like, 'No, I'm good'!"
- "I'm glad that, that the doctors are available to answer my questions and to prescribe (pain) medication, and I think I have been with my doctors awhile, so they know me and I know, them, which, I think makes for a better relationship."

PAIN MANAGEMENT INFORMATION/EDUCATION (n=15, 71%)

- "I did receive instructions from the nurse at the hospital, and then also, there was like a little pamphlet that came with it explaining like what the dosage should be, how often to take it, and that it could become, I guess, addictive, or whatever…"
- "I believe every time I was handed written instructions, every single time--20 years ago, 10 years ago, every time I've had something done. I'm always handed written instructions."

POSITIVE ATTITUDE TOWARD OPIOID ANALGESIA (n=9, 43%)

- "Oh, I love opioid pain management…it was always my opinion that if somebody is in intense pain and they need the opioid, let 'em have it. So they can get addicted, so what? I mean, you can't live in pain. And if it's the only thing that will alleviate the pain, why not provide it to the patient? I can't see restricting it because, because of fear of addiction…addiction is not a good thing, but it's probably not as bad as being in intractable pain."
- "If they're in bad enough pain, and this is what they desire, and this is what they should get in order to control their pain. And everybody deserves to have their pain taken care of with a pill, a shot, whatever. I just think that everybody, everybody, should have a good life."

WELL-MANAGED PAIN PERI/POSTOPERATIVELY (n=9, 43%)

- "I took Tylenol, like I said only couple pills when I came home. And then I ended up not having to take anything else. I mean, I was truly amazed like through the whole process that, after having my surgery, how good I felt."
- "The only issues I had were certainly some post-op discomfort which I controlled easily with Tylenol."
- "…I had surgery, and for 24 hours, I had NO KIND OF PAIN."

COMPLEMENTARY ANALGESIC MODALITIES (n=17, 81%)

- Chiropractor (14%)
- Massage (10%)
- Exercise (29%)
- Heat (29%)
- Ice (48%)
- Topical Anesthetics (57%)

PROACTIVE PAIN MANAGEMENT (n=5, 24%)

- "The first thing I did when I got home is I did take a couple Tylenol, and if it was gonna happen, at least I had a couple Tylenol in me."
- "I cleaned up the area, and spread on the Vitamin E and within a short length…a few days, pain from that area, the raw opened wound pain, went away…I was able to manage that on my own."

POSITIVE PSYCHOSOCIAL ASSETS (n=15, 71%)

- "I actually have a lot of support. I have a very supportive family. I have a husband, I have two sisters I'm really close to, I have friends, and I talk to a couple of women or acquaintances on line who either had breast cancer or were going through breast cancer, so that was helpful, and that was nice."
- "I think that's what took me through it, and not only that, so have a good network, 'cause I have very good friends, you know, like…they will come and bring meals for me and you know we sit down and we talk about everything. I would say that helps me a lot. A good network, a good family life, and they will get you through it."

* Themes within this category are indicated by bold caps. Percentages are based on the number of participants reporting on those themes during interviews. Exemplary quotes are bulleted underneath each.

Figure 5. Facilitators of optimal pain management – exemplar quotes from interview data

5.4.3 Challenges to optimal pain management

The ten themes and exemplary quotations for this category are shown in Figure 6. The most frequently occurring theme under this category was ineffective interactions with the care team (n=21, 100%). For example, two participants described situations in which healthcare providers offered no pain management interventions due to the absence of objective evidence of pain (e.g., diagnostic testing revealed no structural cause for the pain). Several expressed frustration with seeing different providers during cancer center follow-up visits resulting in fragmented care while others were unaware of who to contact when experiencing acute onset or undermanaged chronic pain.

Other participants shared that lack of sufficient information (n=17, 81%) impeded effective pain management. For example, nine (43%) study participants endorsing pain at the time of the interview denied receiving education regarding evidence-based pain management strategies or information about analgesic options or available non-analgesic strategies.

Attitudes contributing to opioid stigma (n=18, 86%) also emerged as a challenge to optimal pain management. Participants' attitudes and behaviors indicative of opioid stigma included avoiding opioids due to multiple reasons including fears of addiction, adverse effects, and believing their pain did not warrant treatment with opioids, despite describing the pain as undermanaged. Others avoided the topic of opioid analgesia or denied ever requiring them for pain management after previously reporting otherwise (n=5, 24%). Four participants (19%) described provider reluctance as an attitudinal challenge to optimal pain management; for example, one participant's physician focused on pinpointing the cause of the pain and became evasive when asked about prescribing analgesia.

Medical conditions precluding them from employing certain analgesics were identified by six (29%) interview participants. One avoided ibuprofen due to chronic kidney disease; another avoided nonsteroidal anti-inflammatory drugs (NSAIDs) due to inflammatory bowel disease; and a participant with hypertension limited the number of steroid injections she received, as they increase blood pressure.

Complication of pain management by chronic comorbid conditions was endorsed by 90% (n=19) of participants. Examples of these conditions included rheumatoid arthritis, osteoarthritis, and fibromyalgia. Participants endorsing pre-existing undermanaged pain at the time of the interview (n=17, 81%) described managing new onset pain in addition to chronic pain, which one participant described as "everyday pain," as challenging. Two participants delayed reporting acute pain until it intensified to the point of requiring emergency intervention because of being accustomed to constant pain.

During interviews, 62% (n=13) relayed unhelpful behaviors or attitudes impeding optimal pain management (e.g., expressing dislike for taking medication, avoiding oral analgesics). One participant described herself as "too lazy" to comply with physician recommendations. Others accepted pain as a normal part of aging, including some resigned to experiencing pain for the remainder of their lives.

Psychological distress and other negative influences posed challenges to pain management for 33% (n=7) of the participants. Some reported experiencing pain daily, limiting daily activities and decreasing quality of life, frequently resulting in anxiety and depression. Others recounted negative life events or received information that influenced pain management decisions (e.g., caring for loved ones who experienced intense pain, hearing stories about others' negative pain experiences).

INEFFECTIVE CARE TEAM INTERACTIONS (n=21, 100%)

- "I called the Cancer Center…they didn't want to reorder the gabapentin. They said they didn't have it on my file. I said, 'That's not my problem. I have, in my hand, a prescription that was given to me…by the nurse practitioner for gabapentin.' And they said, once again, 'Go see your PCP, and maybe you need to see an endocrinologist.' I'm like, 'Say what? What in the world would I see an endocrinologist for? OK…I don't understand. When you prescribed this, your group, and now, I can't get a prescription for it, and I still have peripheral neuropathy, which the drug is prescribed for peripheral neuropathy…"
- "You wanna walk in, feeling like these people know you, like they care about you, like you're seeing…the same person more than once. You don't wanna feel like you're getting shuffled in there, kind of like a number, and then shuffled out again. And, I mean, I've had to correct PAs about you know, this infection I had."

INSUFFICIENT INFORMATION TO MANAGE PAIN (n=17, 81%)

- "…other than like I said, just take the Tylenol or whatever, they really haven't been anybody that have given me any other ideas on how to manage it."
- "Whatever they told me, I did. I can't really remember, to tell you the truth…"
- "I don't even know if I was even supposed to…there was something over the counter they told me I could take, I don't even know if it was Tylenol, I don't know what it was…really, I can't remember."

MANIFESTATIONS OF OPIOID STIGMA (n=5, 24%)

- Memo from interviewer C.H., "Did not even let me give examples of opioids before stating that she would not take (opioids) unless 'absolutely necessary.' "
- Memo from interviewer K.A., "At the mere mention of opioid pain medicine, she stopped me and denied ever employing or desiring to employ them for pain management."

ATTITUDES CONTRIBUTING TO OPIOID STIGMA (n=18, 86%)

- "I think it's OK to use opioid pain medicine when the pain is so severe that really people can't function without it, and of course, when people are severely injured, or have terrible, terrible pain, or they have terminal diseases, that kind of treatment is fine or for short term pain reduction, if there's nothing else that's going to work."

ADVERSE EFFECTS FROM ANALGESICS (n=10, 48%)

- "I started on Celebrex, and that was reasonably good. I took it for years, then it bothered my stomach really bad, so I had to stop the Celebrex."
- "They gave me pain pills and muscle relaxers so that my blood pressure was 60 / 40 at some point."

CONTRAINDICATIONS TO ANALGESICS (n=6, 29%)

- "When I last saw my kidney doctor, and I was talking to her about possible knee surgery, she said to have the physician call her because they want to give very high doses of NSAID post-op, not PRN, but taken routinely. And she said she would rather see her patients on short term opioids for pain, than all the things that could destroy your kidneys."

OTHER CONDITIONS COMPLICATED PAIN MANAGEMENT (n=19, 90%)

- "In my left knee that I had a torn meniscus, I also had a fracture. And he said he didn't even wanna do surgery, because he says the combination of things you have there, if I did surgery on the meniscus, it's just gonna make the whole business worse."
- "…the only thing they can find is I have an extra vertebrae…and they're not really sure that creates a problem because primarily, the pain that I have goes from my shoulder blade all the way down into my hip…"

PRE-EXISTING UNDERMANAGED PAIN (n=17, 81%)

- "I have rheumatoid arthritis, so I was sort of like, used to pain. I have pain every day…"
- "If you were to say to me, 'what's your pain on a level from 0 to 10 every day,' I probably say it's about a 6."

UNHELPFUL ATTITUDES/BEHAVIORS (n=13, 62%)

- "I'm 77 years old, and I'm going to have aches and pains, and I know that. [laughs]"
- "With pain, I am a person who does not like to take medication."

PSYCHOLOGICAL DISTRESS/NEGATIVE INFLUENCES (n=7, 33%)

- "…dealing with this pain all the time can really pull you down."
- "When you're in pain for a long period of time, I really think all kinds of other things can coalesce to make your whole experience bad. Depression sets in, you feel like you're never gonna get any better, that in turn brings you down more, makes you more reluctant to even try to exercise, try physical therapy…you just lose hope (starting to cry) that you're ever going to get better. "

* Themes within this category are indicated by bold caps. Percentages are based on the number of participants reporting on those themes during interviews. Exemplary quotes are bulleted underneath each.

Figure 6. Challenges to optimal pain management – exemplar quotes from interview data

5.4.4 Other factors affecting optimal pain management

This third category included three themes, shown in Figure 7, not clearly aligning with either facilitators or challenges. Participants (n=9, 43%) attributed pain to the effects of cancer treatment modalities, including surgery, radiation, chemotherapy, and most frequently, aromatase inhibitors (AIs). Thus, definitively determining whether pain was new in onset, a side effect of cancer treatment, or exacerbations of other conditions (e.g., rheumatoid arthritis, osteoarthritis) was not possible.

Patients' understanding of or willingness to adhere to a pain management plan was the second theme under this category (n=8, 38%). Codes under this theme were difficult to attribute to lack of a predetermined pain management plan or the participants' limited ability to recall past pain management experiences accurately, as some referred to pain management experiences which occurred years before their breast cancer diagnoses.

Some participants (n=7, 33%) described internal and external psychosocial influencers (e.g., perceptions of life events and their effects) as factors affecting their pain experiences. One participant attributed hearing about "kids" getting "addicted to this and that" leading to "toughing it out" rather than treating her pain while others acknowledged family members' prior struggles with pain management influenced pain treatment practices.

PAIN ATTRIBUTED TO EFFECTS OF CANCER TREATMENT (n=9, 43%)

- "I had more pain from where she took out the lymph nodes than I had from when she took out the lump, but my doctor said that that's probably what would happen, so I sort of expected it. I didn't have too much pain from the radiation. I was more tired, and then I think it bothered my arthritis."
- "They [aromatase inhibitors] all have one thing in common: they're going to affect joint pain, muscle pain--which I had that to begin with--so I feel that some of this that's so bad is connected with that drug."
- I had so many neurological problems [from the chemotherapy], they were afraid that they would not be reversible, and as a result, the peripheral neuropathy never was reversible. I still have it today—now, that's painful! It was in my whole hand, and my feet were like blocks of wood. That was very difficult 'cause I couldn't walk well. I couldn't feel the pedals on the car, the brake, or the gas, so I didn't drive during that period of time. It hurts to walk on numb feet…and my hands, I couldn't pick anything up."

PATIENT'S UNDERSTANDING OF/WILLINGNESS TO ADHERE TO PAIN MANAGEMENT PLAN (n=8, 38%)

- "I think I took…she gave me some pain pills. I think I took them the day I got home from surgery…yeah, maybe that day and one the day after."
- "I did take it [opioid analgesia] because they told me to. I guess the pain never had a chance to take hold because I never experienced any problem when the pain medication ran out. I was…fine."

INTERNAL AND EXTERNAL PSYCHOSOCIAL INFLUENCERS (n=7, 33%)

- "So there is a certain psychological component to care too, as far as addressing pain. It's just not a question of, you know, take two of these and three, you know three of these a day, and then we'll see in a week how that works."
- "I was so stressed out I didn't know what to do! I mean, I was having panic attacks, which is a form of pain to me…the thought of cancer, and what that's going to mean to my life now."

* Themes within this category are indicated by bold caps. Percentages are based on the number of participants reporting on those themes during interviews. Exemplary quotes are bulleted underneath each.

Figure 7. Other factors affecting optimal pain management – exemplar quotes from interview data

5.5 Discussion

Our findings regarding facilitators of optimal pain management were consistent with those reported in the literature, including patient-centered pain communication; well-managed peri/postoperative pain; willingness to employ complementary analgesic modalities; and proactive pain management. We describe how each facilitator reflects the existing literature below.

The majority of participants described at least one patient-centered clinical interaction regarding pain management in which communication focused on needs and preferences and conveyed healthcare providers' concern for their well-being and willingness to honor their values (Reeve et al., 2017). This finding aligns with those of Ruben et al. (2018), who concluded that patient-centered communication in patients with cancer is conducive to optimal pain management, which is associated with higher levels of pain self-efficacy and reduced impacts of pain intensity and pain interference. Patient-centered communication is particularly important for cancer care in which multiple specialists are involved, requiring optimal coordination and communication among clinicians to effectively address patients' difficulties (Reeve et al., 2017) including undermanaged pain. Well-coordinated care facilitates continuity of care, which is paramount to adults aged 65 and older feeling comfortable reporting pain to their care teams (Minaya-Freire et al., 2020).

The present study and our prior study of pain among women aged 65 and older with breast cancer (Alsbrook et al., 2021) reflected that participants' pain was well-managed overall during the time of their respective breast surgeries. We considered this finding a facilitator of optimal pain management in our sample, as well-managed pain at these early timepoints is crucial to optimal outcomes for patients treated for breast cancer (Brenin et al., 2020). The majority of participants reporting pain beyond these early timepoints attributed their pain to chronic conditions not related to breast cancer treatment.

Participants recounted enacting measures to proactively manage pain (e.g., self-administering analgesia upon discharge after surgery, performing wound care to manage pain resulting from radiation burns). Proactive pain management enables patients with cancer to live as independently and with as tolerable a level of pain as possible (Scarborough and Smith, 2018).

Our findings regarding challenges to optimal pain management were also consistent with those reported in the literature, including ineffective care team interactions; insufficient pain management information; opioid stigma; unhelpful attitudes and behaviors; pre-existing undermanaged pain; and psychological distress and other negative influences. We describe how these challenges reflect the existing literature below.

Participants identified ineffective care team interactions as disruptive of regular coordination of services, a central tenet of comprehensive pain management (Gatchel et al., 2014). Inconsistent care coordination poses a health system-level barrier to pain management among patients with cancer (Luckett et al., 2019). Another disconcerting finding was the paucity of participants who denied having a predetermined plan for preventing undermanaged chronic pain and/or managing new-onset acute pain, including those with chronic painful conditions (e.g., rheumatoid arthritis, peripheral neuropathy). The literature provides multiple possible reasons. Steenbergen et al. (2022) cited lack of understanding of options, inability and/or unwillingness to communicate values and preferences, and negative prior experiences of conveying new onset acute pain or undermanaged chronic pain to their care teams as barriers. According to Tyson et al. (2021), patients with breast cancer from racial/ethnic minority groups tend to neither ask for nor receive pain management information, as they are often hindered by cultural values, beliefs, and/or language barriers.

Several participants' responses embodied opioid stigma manifested in negative attitudes, stereotypes, and judgments regarding those who employ opioid analgesia (Bulls et al., 2022). Others reported "mental blocks" against opioids and would not consider them an option for pain management. Kwekkeboom et al. (2021) attributed the increase in negative attitudes and behaviors surrounding opioid analgesia over the past 20 years to increasing attention to the ongoing

opioid crisis in the United States. Fitzgerald et al. (2017) identified historical misconceptions including fear of addiction and side effects as barriers to optimal pain management among adults aged 65 and older, who are apt to hold misconceptions regarding opioid pain management (Krishnamani et al., 2022). This study and one by Graabæk et al. (2021) found a general dislike of taking medications as a barrier to care for adults aged 65 and older. Others accept pain as a normal part of aging with some resigned to lifelong pain, consistent with the findings of Meghani et al. (2020).

Some participants attributed psychological distress (e.g., feelings of hopelessness, anxiety and depression) to ongoing undermanaged pain. These responses reflect the results of prior research among patients with cancer (Amaram-Davila et al., 2020) and adults with chronic pain (Budge et al., 2020). Caraceni and Shkodra (2019) recommend comprehensive assessments of all patients with cancer to identify challenges and capitalize on psychological strengths to prevent and overcome difficulties. These strengths include resilience (Colley et al., 2017), which Zapater-Fajarí et al. (2021) associate with successful aging and high-level functioning, and the skillset of self-advocacy in cancer survivorship, defined by Thomas et al. (2020) as an individual's aptitude for mitigation of obstacles encountered when seeking to meet their needs aligned with their preferences and values.

Our themes under the category of factors affecting optimal pain management (pain attributed to effects of cancer treatment, patient's understanding of and/or willingness to adhere to a pain management plan, internal and external psychosocial influencers) did not cluster under the category of either facilitators of or challenges; however, these findings aligned with the literature. Patients with cancer aged 70 and older receiving treatment with AIs in a study by Germain et al. (2017) also attributed their pain to treatment. A literature review conducted by Scarborough

and Smith (2018) identified adherence to a safe, effective pain management plan as a key factor in optimal pain management. Finally, Kwekkeboom et al. (2021) reiterated the detrimental effects of internal (e.g., erroneous beliefs regarding opioids) and external (e.g., stories shared by family or other acquaintances involving opioids) psychosocial influencers our participants also reported. Further research is needed to clarify the context and conditions by which these factors affect optimal pain management among women aged 65 and older treated for breast cancer.

5.6 Limitations

A limitation of the study was that, to be eligible, participants had to have reported pain $\geq$ 4/10 on the NRS at least once during parent study participation without stipulating its cause, location, or frequency. Thus, participants' descriptions of their pain management experiences were not necessarily related to surgical treatment of cancer. Yet, our findings revealed that pain from chronic comorbid conditions was common among women aged 65 and older treated for breast cancer. Recall bias also limited the interpretation of the findings, as participants relayed events surrounding their initial breast cancer surgery which, for all but three participants, took place from one to three years prior. This may explain why some participants failed to recall pain mitigation strategies (e.g., identifying a care team contact, establishing a pain management plan). Reviewing clinical notes regarding pain management in future studies may provide more accurate and timely insight into identifying this as a barrier to optimal pain management. Additionally, due to postsurgical practice changes, opioid analgesic prescriptions following breast cancer surgery significantly decreased after the first year of data collection for the parent study. Thus, responses to questions regarding post-discharge analgesia differed between participants inter-

viewed three years after breast surgery and those of more recently recruited participants. However, we achieved our goal to gather participants' self-reported perceptions of pain management experiences and influencing factors regardless of etiology, course, or onset.

5.7 Implications for nursing

Oncology nurses are uniquely qualified to champion optimal pain management to counteract the challenges and other factors revealed in this study. For example, all participants gave responses coded to ineffective care team interactions, a problem greatly decreased by well-coordinated care facilitated by nurses. Additionally, the high percentage of opioid stigma detected among participant responses can be counteracted by nurses providing pain management education to patients and their families. Our findings, combined with mitigation strategies to promote optimal pain management among patients with cancer shown in Figure 4, provide a framework for future research aimed at promoting facilitators and addressing challenges to optimal pain management among women aged 65 and older treated for breast cancer.

5.8 Conclusion

This study involving women aged 65 and older who underwent surgery for breast cancer elucidated facilitators of optimal pain management including patient-centered communication, education regarding pain management, positive attitude toward opioid analgesia, willingness to employ multimodal analgesia, proactive pain management, and reliance on psychosocial assets

(e.g., self-advocacy, resilience). Challenges to optimal pain management included ineffective care team interactions, opioid stigma, adverse effects from and contraindications to analgesics, chronic conditions and pre-existing pain complicating pain management, and psychological distress. Pain attributed to cancer treatment, analgesia plan adherence, and psychosocial influencers emerged as factors also affecting pain management. Future research that builds the evidence for optimal pain management strategies will translate into best care practices for women aged 65 and older treated for breast cancer and improve functionality and quality of life.

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6.0 Quantitative manuscript (Aim 2): Factors affecting pain management in women aged 65 and older with breast cancer

Presented here is the full-text version of the manuscript submitted for publication to the *Journal of Pain and Symptom Management*.

6.1 Abstract

Context. Women with breast cancer aged 65 and older continue to experience undermanaged pain, and the factors that contribute to this ongoing phenomenon are unclear.

Objectives. Describe the associations among self-reported: 1) levels of self-advocacy; 2) patient-centeredness of communications with healthcare providers; 3) stigma regarding opioid use and addiction; and 4) ratings of pain intensity among a cohort of women with breast cancer aged 65 and older.

Methods. This cross-sectional study employed a descriptive, correlational design. Participants aged 65 or older from a cohort of women treated for breast cancer completed reliable and valid questionnaires that included scales for self-advocacy, patient-centered communication, opioid stigma, and pain intensity.

Results. The sample included 73 participants (mean age=73.03 years, range=65-85); the majority (89%) were non-Hispanic White. Correlation analyses revealed negative associations between patient-centered communication and pain intensity [$r_b(71) = -.323$, $p=.005$] and opioid stigma agreement and pain intensity [$r_b(71) = -.238$, $p=.042$]. Positive associations were identified between patient-centered communication and self-advocacy [$r(71) = .448$, $p<.001$]; specifically, patient-centered communication positively correlated with each of the self-advocacy subscales: informed decision-making [$r_s(70) = .440$, $p<.001$], effective communication [$r_s(69) = .378$, $p=.001$], and connected strength [$r_s(71) = .336$, $p=.004$] subscales.

Conclusion. Women aged 65 and older treated for breast cancer reporting higher patient-centered communication with their oncology care teams were more likely to report lower pain scores and indicate higher self-advocacy skills. Future studies examining these relationships

among different populations of women aged 65 and older with breast cancer will enhance the understanding of factors driving optimal pain management.

Key Message: This study describes associations among factors known to affect pain management among patients with cancer in a cohort of women aged 65 and older treated for breast cancer. Findings indicate that communications perceived as patient-centered were associated with lower pain intensity and stronger propensity to self-advocate for cancer care needs.

6.2 Introduction

Much focus has been placed on advancements in treatment for patients with cancer pain and revisions to analgesic guidelines. However, cancer-related pain remains undermanaged (Krishnamani et al., 2022) and continues to be a significant problem among adults aged 65 and older, the population in which cancer prevalence is highest (Brant, 2018). Furthermore, the problem of managing pain in adults with cancer aged 65 and older is often compounded by the need to manage pain for multiple other comorbidities (Williams et al., 2018). If pain remains undermanaged, adults aged 65 and older incur far-reaching and long-term consequences including debility, loss of function, and treatment delays leading to disease progression, all of which decrease quality of life and increase healthcare costs (Brant, 2018). Conversely, adults aged 65 and older whose pain is well-managed report lower rates of morbidity, mortality, hospitalization, and overall healthcare costs (Rajan & Behrends, 2019).

The majority of patients with cancer collaborate with their care teams to manage symptoms resulting from cancer and cancer treatment including pain. However, adults over 65 years of age, patients with less education, lower income, and less resilience are at higher risk for preferring a more passive role in the healthcare decision-making process (Colley et al., 2017). This indicates the need for adults with cancer aged 65 and older to develop self-advocacy skills to meet cancer care needs, including making informed decisions; communicating effectively with one's healthcare team; and connecting to others through shared support and strength (Thomas et al., 2020).

Adults with cancer who are aged 65 and older encounter multiple barriers to optimal pain management. While opioids continue to be the optimal treatment modality for moderate to severe cancer-related pain (Wright et al., 2019), repercussions from the opioid crisis have stigmatized

opioid analgesia (Page & Blanchard, 2019), resulting in restricted options for patients to effectively manage their pain (Kwekkeboom et al., 2021; Martinez Tyson et al., 2021). Opioid stigma manifests itself in patients' fears of adverse effects from opioids including addiction, sedation, experienced and/or anticipated judgment from others regarding their choice to employ opioid analgesia (Bulls et al., 2022). Moreover, opioid stigma impairs direct communication regarding pain status and management between patients with cancer and their healthcare providers (Bulls et al., 2022). Reluctance on the part of patients with cancer aged 65 and older to discuss new onset acute pain or undermanaged chronic pain with healthcare providers renders management of pain and other cancer-related difficulties especially challenging in this population (Brunello et al., 2019), as pain often signals disease progression that would necessitate a shift in priority to urgent diagnosis and treatment (Alsharawneh & Hasan, 2021). This is further complicated by the paucity of clinically focused research involving adults with cancer who are aged 65 and older, particularly research targeting function and management of symptoms such as pain associated with cancer (Haase et al., 2021).

Research aimed at understanding and managing pain among women is also lacking, partly due to exclusion of women from clinical trials, which has caused possible bias among treatment options available to women versus men (Keogh, 2022). This fact is particularly disconcerting, as 70% of individuals in the United States who endorse chronic pain are women (Kiesel, 2017), and inherently painful conditions such as arthritis and fibromyalgia are more prevalent among women (Terplan, 2017). Additionally, women who are older often hesitate to advocate for healthcare needs such as optimal pain management during interactions with physicians who they perceive to be authority figures (Burkhart et al., 2020; Kahana et al., 2018), as they fear being viewed as aggressive or problematic. This tendency for women aged 65 and older not to self-

advocate for their needs may be an important impediment to achieving adequate pain management.

Breast cancer is the most common type of cancer, and its prevalence is highest among females over 65 years across races and stages (SEER, 2022). Due to the high prevalence of breast cancer among women aged 65 and older, and in order to gain deeper understanding of the factors that affect pain management in this population, the purpose of this study was to describe associations among patient self-advocacy; patient-centered communication; opioid stigma; and self-reported pain intensity in a cohort of women aged 65 and older treated for breast cancer.

6.3 Methods

6.3.1 Study design

This cross-sectional study employs a descriptive, correlational design. The University of Pittsburgh's Human Research Protection Office approved the study (STUDY22010102).

6.3.2 Participants

Study participants were recruited from a cohort of women with breast cancer enrolled in Study participants were recruited from a cohort of women with breast cancer enrolled in a large, longitudinal study (N=356) entitled "Genomic Underpinnings for Breast Cancer Treatment-Induced Nausea and Vomiting" (NR016695, S. Wesmiller, PI). Accrual for the parent study occurred at two hospitals within the University of Pittsburgh Medical Center (UPMC): Magee

Womens Hospital and UPMC East. Both hospitals are affiliated with the UPMC Hillman Cancer Center Comprehensive Breast Care Program. Inclusion criteria for the parent study required that the participant be aged 18 to 90 years old with a diagnosis of early-stage breast cancer defined as American Joint Committee on Cancer staging criteria classification (7th edition) stage I, II, or IIIa (Edge et al., 2010); no clinical evidence of distant metastases; and scheduled for breast surgery anticipated to last 4 hours or less. Exclusion criteria included a previous history of neurologic conditions, such as stroke, head injury, spinal cord injury, and intracerebral hemorrhage. All parent study participants aged 65 or older as of May 1, 2022 who had completed at least one year of data collection (n=144) were invited to participate in the present study.

6.3.3 Sample size justification

G*Power® 3.1.9.2 (Faul et al., 2009) was used to estimate an adequate sample size to detect statistical significance with a medium correlation value (r=0.3) (Cohen, 1988). At a power level of 0.8 and alpha level of 0.05, the recommended sample size was 64 participants. Eighty-three participants expressed interest in participating, and 73 participants completed data collection, exceeding the recommended sample size of 64 participants.

6.3.4 Data collection

We reviewed demographic data collected during parent study participation to determine We reviewed demographic data collected during parent study participation to determine eligibility for the current study. Individuals meeting inclusion criteria were approached to participate via either telephone or email based on patient preference. After agreeing to participate, participants

who chose to complete paper versions of the questionnaire were mailed copies of the questionnaire and consent form; a preaddressed, deidentified, postage-paid envelope; and a note card with instructions for completion. Participants who chose to complete digital versions of the questionnaire were emailed an electronic copy of the consent form to sign prior to gaining access to a secure link to the questionnaire using the Qualtrics® online survey software platform (Qualtrics, Provo, UT). Participants who did not respond within three weeks received reminders to complete the questionnaire by their preferred method of contact. After four weeks, all nonrespondents received a final reminder telephone call and were offered the option to complete the questionnaire verbally over the phone.

6.3.5 Questionnaires

A questionnaire was developed that included items from four validated instruments to explore factors that affect pain management. Each of the four instruments are described below.

6.3.5.1 Female Self-Advocacy in Cancer Survivorship scale

The Female Self-Advocacy in Cancer Survivorship (FSACS) scale is a 20-item, Likert type scale measuring the ability of women with cancer to demonstrate three hallmark behaviors that serve to meet their individual needs: making informed decisions about healthcare, communicating effectively with healthcare providers, and balancing giving support to and receiving support from friends and family (Hagan et al., 2018b). Total and subscale scores (informed decision-making, effective communication, and connected strength) are reported for overall and specific self-advocacy behaviors, respectively (Hagan et al., 2016). Psychometric evaluation among a population of adult females between the ages of 21 and 95 years who received an invasive cancer

diagnosis supported the reliability and validity for the total and subscale scores (Hagan et al., 2018a). Possible overall FSACS scores range between 20 and 120 with subscale scores for informed decision-making and connected strength ranging between 7 and 42 and effective communication between 6 and 36; higher scores indicate higher propensity for self-advocacy skills (Hagan et al., 2018a).

6.3.5.2 Patient-Centered Communication in Cancer instrument (short form)

The six-item Patient-Centered Communication in Cancer Care Instrument (PCC-Ca-6) contains six questions that assess each aspect of the six core functions of patient-centered communication: 1) fostering healing relationships; 2) facilitating the exchange of information; 3) responding to emotions; 4) managing uncertainty; 5) making decisions; and 6) enabling patient self-management (Epstein & Street, 2007). Psychometric evaluation of the PCC-Ca-6 among a population of adults whose mean age was 66.7 years who received a colorectal cancer diagnosis suggested excellent overall reliability (Cronbach's α=.92); construct validity was evaluated by examining known-groups validity and convergent validity of the PCC-Ca measures (Reeve et al., 2017). The scores for the six core functions are averaged for a possible average score between 1 and 5; higher scores indicate the perception that participants' healthcare providers communicate well with them (Reeve et al., 2017).

6.3.5.3 Brief opioid stigma scale

The Brief Opioid Stigma Scale is a theoretically based measure of opioid-related stigma among individuals with opioid use disorder (OUD) designed by Yang et al. (2019). This study employed two of its three subscales: Stereotype Awareness (the individual's awareness of stigmatizing attitudes of the general public toward opioids and persons with OUD) and Stereotype

Agreement (the extent to which the individual agrees with these stigmatizing attitudes) (Yang et al., 2019). Psychometric evaluation of these two subscales in a 73.8% male population of persons with documented opioid use disorders between the ages of 18 and 59 supported acceptable construct validity (evidenced by consistent associations between the subscales and theoretically-similar substance abuse stigma scales) and reliability (alpha=0.72 and 0.68, respectively) (Yang et al., 2019). Scores for both subscales can range between 4 and 20. Higher scale scores indicate a higher tendency for the individual to ascribe to opioid-related stereotypes (Yang et al., 2019).

6.3.5.4 Patient-Reported Outcomes Measurement Information System Scale for Pain Intensity (PROMIS® Scale v2.0 – Pain Intensity 3a)

The PROMIS® Scale v2.0 – Pain Intensity 3a includes three items rating patient pain from "No pain" = 1 to "Very severe" = 5. The first two items assess pain intensity over the past seven days while the last item asks patients to rate their pain intensity "right now" ("PROMIS® Pain Intensity - Scale and Scoring," 2020). The scores for each item for each participant were totaled to calculate a raw score which was converted to an interpretable T-score using the scoring table provided as an appendix to the scale. The lowest possible raw score of "3" indicates a response of "no pain" to all three items and converts to a T-score of 36.3 whereas the highest possible raw score of "15" indicates a response of "very severe" pain and converts to a T-score of 81.8 ("PROMIS® Pain Intensity - Scale and Scoring," 2020).

6.3.6 Data analyses

Age, race/ethnicity, and breast cancer surgery type were obtained by participant chart review. A research assistant double-entered 20% of the data to verify accuracy (Day et al., 1998)

which revealed an error rate less than 1%. These errors were located within the dataset, compared with participant responses, and corrected. Data were analyzed using IBM®'s Statistical Package for the Social Sciences (SPSS®) for Windows, Version 27 (IBM, 2020). Descriptive statistics are reported as frequencies (n) and percentages (%) for categorical variables. Scale variables are described with the mean, standard deviation, median, overall and interquartile range. Correlational analyses were conducted using Pearson *r* when assumptions of linearity, normality, and homoscedasticity were met; Spearman rho (r_s) was used when these assumptions were violated. Biserial correlation (r_b) was used when one of the variables was dichotomized. The level of statistical significance was set at an alpha level of 0.05. Assumptions of linearity and homoscedasticity were assessed using scatterplots, normality was assessed using Q-Q plots, and Tukey's criteria was used to identify potential univariate outliers.

6.4 Results

6.4.1 Sample characteristics

Sample characteristics (n=73) are summarized in Table 8. Ages ranged from 65 to 85 years, and mean age was 73.03 ± 5.25 years. The majority (n=55, 75%) underwent segmental mastectomies. Time elapsed between initial breast cancer surgery and date of participation in the present study ranged between 1.15 and 4.16 years with the majority (n=34, 46.6%) over three years post-surgery. The majority of our sample (n=65, 89%) was non-Hispanic White. Although the category "Race/Ethnicity" was analyzed and reported in Table 8, it was not included as a variable in the analyses due to the homogeneity of the sample.

Table 8. Participant characteristics (N=73)

	n (%)	Mean (±SD)
Age (Years)		73.03 ± 5.25
65-70	24 (33%)	
71-74	21 (29%)	
75-80	21 (29%)	
81 or older	7 (9%)	
Number of Years between Initial Breast Surgery and Participation in Present Study		2.68 ± 0.90
1-1.99 years	20 (27.4%)	
2-2.99 years	16 (21.9%)	
3-3.99 years	34 (46.6%)	
over 4 years	3 (4.1%)	
Breast Cancer Surgery Type		
Unilateral segmental mastectomy	53 (72.6%)	
Bilateral segmental mastectomy	2 (2.7%)	
Unilateral total mastectomy	10 (13.7%)	
Bilateral total mastectomy	8 (11.0%)	
Race and Ethnicity		
Black (non-Hispanic)	8 (11%)	
White (non-Hispanic)	65 (89%)	

6.4.2 Questionnaire scores

Descriptive statistics of the scale and subscale scores included in the analyses are listed in Table 2. Participants reported moderate to high overall self-advocacy ($\overline{x}$ ± SD = 97.45 ± 10.04, possible range 20 to 120) and subscale measures of informed decision-making ($\overline{x}$ ± SD = 36.10 ± 4.04, possible range 7 to 42), effective communication ($\overline{x}$ ± SD = 30.17 ± 4.15, possible range 6 to 36), and connected strength ($\overline{x}$ ± SD = 31.18 ± 5.82, possible range 7 to 42); and perceived patient-centered communication ($\overline{x}$ ± SD = 4.06 ± 0.716, possible range 1 to 5). Opioid stigma measures for stereotype awareness ($\overline{x}$ ± SD = 11.73 ± 3.61, possible range 4 to 20) and stereotype agreement ($\overline{x}$ ± SD = 9.36 ± 3.23, possible range 4 to 20); and pain intensity scores ($\overline{x}$ ± SD = 44.44 ± 10.78, possible range 36.3 to 81.8) were all relatively low.

Table 9. Summary statistics of measures employed in study (N=73)

Measures	Mean (±SD)	95% CI	Observed Range	IQR
Total FSACS scores	97.45 ± 10.04	95.07 – 99.83	70 - 120	14
Informed Decision-Making	36.10 ± 4.04	35.14 – 37.06	27 – 42	6
Effective Communication	30.17 ± 4.15	29.19 – 31.15	21 - 36	6
Connected Strength	31.18 ± 5.82	29.81 – 32.56	11 – 42	7
Patient-Centered Communication in Cancer Care scores (short form)	4.06 ± 0.716	3.89 – 4.23	2.17 – 5.33	1.17
Brief Opioid Stigma Scale				
Stereotype Awareness	11.73 ± 3.61	10.88 – 12.59	4 – 19	5
Stereotype Agreement	9.36 ± 3.23	8.60 – 10.11	4 – 15	5
PROMIS® Scale v2.0 - Pain Intensity 3a T-Scores	44.44 ± 10.78	41.88 – 46.99	36.3 – 72.0	15.10
Dichotomized Pain Scores	**Pain – Yes (T-Score >36.3)**		**Pain - No**	
	30 (41.1%)		43 (58.9%)	

IQR=Interquartile Range
FSACS=Female Self-Advocacy in Cancer Survivorship
PROMIS=Patient-Reported Outcomes Measurement Information System

6.4.3 Correlation analyses

The results of the correlation analyses are displayed in Table 10. Strength of correlations were determined based on Cohen's criteria for strength of association (Cohen, 1988). Pain intensity scores were zero-inflated with over half of participants (58.9%) reporting no pain. Thus, we created a dichotomized pain intensity variable (0=no pain, 1=pain) to linearize the data and calculate a biserial correlation to measure the strength of association between all continuous level variables and the binary variable of dichotomized pain intensity (Laerd, 2020b). Pain intensity

had statistically significant, medium-sized negative correlation with patient-centered communication [$r_b(71) = -.323$, $p=.005$] and a statistically significant, small size negative correlation with opioid stigma agreement [$r_b(71) = -.238$, $p=.042$]. No other statistically significant correlations with pain intensity were found.

A statistically significant, medium to large positive correlation was observed between patient-centered communication and overall propensity for self-advocacy [$r(71) = .448$, $p<.001$]; specifically, patient-centered communication correlated with each of the self-advocacy subscales of informed decision-making [$r_s(70) = .440$, $p<.001$], effective communication [$r_s(69) = .378$, $p=.001$], and connected strength [$r_s(71) = .336$, $p=.004$]. No other statistically significant correlations with self-advocacy were observed.

Table 10. Correlation matrix for instrument scores

	1	1a	1b	1c	2	3a	3b	4
1: Female Self-Advocacy in Cancer Survivorship	1	—	—	—	—	—	—	—
a. Informed Decision-Making	**.737**^{s**}	1	—	—	—	—	—	—
b. Effective Communication	**.711**^{s**}	**.525**^{s**}	1	—	—	—	—	—
c. Connected Strength	**.580**^{s**}	**.245**^{s*}	.018^{s}	1	—	—	—	—
2: Patient-Centered Communication	**.448**^{**r}	**.440**^{s**}	**.378**^{s**}	**.336**^{s**}	1	—	—	—
3: Brief Opioid Stigma Scale	—	—	—	—	—	—	—	—
a. Opioid Stigma Awareness	-.080^{r}	-.097^{s}	-.162^{s}	-.123^{s}	-.126^{r}	1	—	—
b. Opioid Stigma Agreement	-.106^{s}	-.057^{s}	-.083^{s}	-.098^{s}	.004^{s}	**.479**^{s**}	1	—
4: PROMIS® Pain Intensity (dichotomized)	-.090^{b}	.036^{b}	.023^{b}	-.103^{b}	**-.323**^{**b}	-.004^{b}	**-.238**^{*b}	1

*= correlation is significant at the 0.05 level (2-tailed)
**=correlation is significant at the 0.01 level (2-tailed)
r=Pearson correlation
s=Spearman correlation
b=biserial correlation

6.5 Discussion

The findings of this study illustrate relationships among self-advocacy, opioid stigma, patient-centered communication, and pain in women aged 65 and older treated for breast cancer. Notably, we identified that self-advocacy is positively associated with patient-centered communication and that pain intensity is negatively associated with patient-centered communication and opioid stigma.

Despite participants' high overall self-advocacy scores, 41% endorsed experiencing pain. These findings support those of Kolmes' and Boerstler's (2020) who report that women's self-advocacy behaviors are unlikely to be responsible for poor pain management outcomes. This may be because these women's efforts to self-advocate for pain management did not result in improved pain outcomes or that factors other than self-advocacy affect adequate pain management. For example, a study by Chou et al. (2018) revealed that women are less adherent than men to prescribed analgesia regimens; more likely to hide their true perceptions of pain; and that women's level of education and perception of a trusting patient-provider relationship affect analgesia adherence and pain reporting. Future studies that explore associations between self-advocacy and pain intensity are needed to identify possible interrelationships and to pinpoint actionable targets for optimizing pain management among women aged 65 and older with breast cancer.

The negative association between patient-centered communication and pain intensity indicates that participants reporting higher pain intensity scores perceive that their healthcare providers do not communicate well with them. This is consistent with findings of Samuel et al. (2020) whose study among patients with breast cancer revealed that participants endorsing a mutually respectful patient-physician relationship were less likely to endorse moderate to severe

pain. Furthermore, Ruben et al. (2018) also found this relationship and additionally reported that higher levels of self-efficacy (a similar but distinct concept from self-advocacy) (Thomas et al., 2020) for chronic disease management significantly mediated this relationship. Since this study also identified positive correlations between patient-centered communication and overall self-advocacy and its three subscales, future research should evaluate the moderating role self-advocacy plays between communication and pain.

The negative association between opioid stigma agreement and pain intensity suggests that those who agree with opioid stigma stereotypes have lower pain scores. This result may reflect the fact that less than half of participants reported pain in the prior seven days. Other potential explanations may include the finding reported by Cagle and Bunting (2017) that stigma contributes to patients' reluctance to openly report their unmanaged or undermanaged pain to their providers. In addition, Azizoddin et al. (2021) found that patients with cancer who endorse stigma often avoid discussions involving opioids or enact other behaviors (such as underreporting pain) to diminish their true need for opioids to avoid being labeled "pill seekers." Opioid stigma stereotype awareness was not associated with pain intensity, which suggests low opioid stigma stereotype awareness does not affect how women treated for breast cancer aged 65 and older perceive their pain.

Neither the opioid stigma awareness nor the opioid stigma agreement scores appeared to be associated with patient-centered communication or self-advocacy. This may be because of the belief among this sample in their overall propensity for self-advocacy, evidenced by its relatively high overall mean score, and that their communication with cancer care providers are predominately patient-centered, evidenced by a moderate mean PCC-Ca-6 score.

6.6 Limitations

One limitation of this study is the different lengths of time since surgery among study participants; thus, there was variation among cancer treatment trajectories. Ultimately, and interestingly, our findings provide much insight regarding pain management experiences across the treatment trajectory since first diagnosis of breast cancer and surgical intervention. Furthermore, we employed the awareness and agreement subscales of the Brief Opioid Stigma Scale, which was psychometrically tested and validated among a predominately male population to measure opioid-related stigma among individuals with opioid use disorder (Yang et al., 2019). As the opioid use status of each study participant is unknown, this further limits our findings yet provided an opportunity to evaluate this measure among a population of women aged 65 and older with breast cancer for insights into their perceptions and opinions regarding opioid analgesia. The generalizability of our findings is also limited by the lack of racial and ethnic diversity among our sample. Finally, men with breast cancer did not participate in either the parent or the present study. Thus, future studies involving a sample more representative of all patients treated for breast cancer who are aged 65 and older would inform opportunities to optimize pain management in this population.

6.7 Conclusions

In this cohort of women aged 65 and older treated for early-stage breast cancer, 41% of study participants continued to endorse pain a year or more past initial breast cancer surgery. Female breast cancer survivors aged 65 and older who perceive clinical interactions to be pa-

tient-centered endorsed greater propensity for self-advocating for their needs and enacting the self-advocacy skills of informed decision-making, effective communication, and connected strength. Scores for pain intensity were negatively correlated with scores of perceived patient-centeredness of clinical communications indicating that patient-centered communication corresponds to lower pain intensity. Future studies should aim to improve the communication dynamic between women aged 65 and older with breast cancer and members of their care teams as a means of optimizing management of their pain and other symptoms associated with breast cancer and its treatment.

Disclosures/Conflicts of Interest: None.

Acknowledgements: The authors would like to thank the past and present members of the Treatment-Induced Nausea and Vomiting study team within the University of Pittsburgh School of Nursing for collecting, managing, and analyzing the parent study data.

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Appendix A IRB approval for qualitative study

University of Pittsburgh | Institutional Review Board
Office of Research Protections

APPROVAL OF SUBMISSION (Expedited)

Date:	September 14, 2020
IRB:	STUDY20060135
PI:	Karen Alsbrook
Title:	Talking pain: Conversations with older breast cancer survivors
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:	9/14/2020
Expedited Category	(7)(b) Social science methods, (7)(a) Behavioral research
Determinations:	• Waiver of consent documentation
Approved Documents:	• Interview Script/Questions • Reminder Letter for Interview • Email Recruiting Script • References for Study Aims • Telephone Recruiting Script • Telephonic Consent Form

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/.

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, Emily Bird.

Please take a moment to complete our Satisfaction Survey as we appreciate your feedback. Human Research Protection Office 3500 Fifth Avenue, Suite 106 Pittsburgh, PA 15213 www.hrpo.pitt.edu

Appendix B Recruiting email for qualitative study

Hello, _____,

Thank you so very much for your participation in the University of Pittsburgh study, "Genomic Underpinnings for Breast Cancer Treatment-Induced Nausea and Vomiting." Our team is interested in conducting a research study in order to learn more about our participants who are 65 years of age and older and their experiences involving pain management and interacting with healthcare providers. We are asking you to participate in a one-time interview to be conducted via telephone at a date and time convenient to you. The interview is expected to last anywhere from 45 minutes to an hour and a half, depending on the depth of the discussion. You may withdraw from the study at any time you choose. We will add $25 to each participant's Vincent card after the interview is completed. After reading this email, if you are interested in participating, please hit "Reply," and please copy, paste, and complete the short form at the bottom of this email. You will receive a call to set up an appointment for the interview from me at (615) 396-7476. I will also mail a copy of the consent form for the study for you to review prior to the scheduled interview along with a letter reminding you of the date and time of our interview.

Our hope is to learn from you how to improve communication about and optimally manage pain in older women with breast cancer. Please feel free to call me at any time at (615) 396-7476 with any questions or concerns regarding this study. Again, we are so grateful to you for being part of the postoperative nausea and vomiting study and for considering participation in this interview study.

Warmest Regards,

Karen E. Alsbrook

Karen Alsbrook, BSN, RN, OCN, PhD Student
The University of Pittsburgh

Appendix C Recruiting telephone script for qualitative study

Hi, this is **(your name)** from the University of Pittsburgh. I'm calling for **(participant's name)**, please. How are you doing?

(Participant's Name), we are so very grateful for your participation in the postoperative nausea study. Our team is interested in learning more about our participants who are 65 years of age and older by giving them the opportunity to share their experiences involving pain management and interacting with healthcare providers. We are calling to asking whether you would be willing to participate in a research project involving one-time interviews that would be conducted via telephone at a date and time convenient to you. The one-time interview is expected to last anywhere from 45 minutes to an hour and a half, depending on the depth of the discussion. You could withdraw from the study at any time you choose. As thanks for participating in this research project, we would add $25 to your Vincent card after completion of the interview.

Would you be interested in participating?

If no: OK, **(participant's name)**, is there any particular reason? Well, thank you, and again, we are so glad to have you on our nausea study. Have a great rest of the day.

If yes: Thank you so much, (participant's name). May we schedule a date and time that are convenient for us to call for you for the interview? (recruiter then obtains date and time). OK, _____, you are all set for (date and time). Do you know if you still have your Vincent card? **(If yes, then fine—if not, please let them know we will reissue a new one, if the interview is completed)**. Is this the number I should call on the day of your interview?

We will be mailing you information about the study and a confirmation of your interview date and time in the mail. If I can answer any questions, or if you need to reschedule your interview appointment, my number is **(your phone number)**. We look forward to your interview on **(day and date)** at **(time)**. Thank you, and have a great rest of the day!

Appendix D Appointment confirmation letter for qualitative study

University of Pittsburgh
School of Nursing

(Date)

Dear (Participant Name):

Thank you for agreeing to participate in our research study that examines older women's perspectives regarding pain management. Our interview questions will focus on your experiences with pain management, including how you treat your pain; your thoughts on pain management methods; and how you communicate with your cancer team about pain.

Please find enclosed the consent form for the study. Prior to beginning your interview, we will confirm that you agree to participate and fully understand the contents of the consent form. Please feel free to reach out to me or your assigned interviewer if you have any questions about giving consent.

This letter is to confirm your availability for a 45 to 90-minute interview that is scheduled to begin at **time** on **day and date**. Please expect a telephone call at that time from **interviewer's name** at **(xxx) xxx-xxxx**. If you prefer to reschedule, have any questions before the interview, or have decided not to participate, please call me directly at (615) 396-7476.

Warmest Regards,

Karen Alsbrook

Karen Alsbrook, BSN, RN, OCN, PhD Student
Principal Investigator

Enclosure

Appendix E IRB-approved copy of verbal consent form for qualitative study

University of Pittsburgh
School of Nursing

TELEPHONIC CONSENT TO ACT AS A PARTICIPANT IN A RESEARCH STUDY

TITLE: Talking pain: Conversations with older breast cancer survivors

PRINCIPAL INVESTIGATOR: Karen Alsbrook, BSN, RN, OCN
kea64@pitt.edu
phone: (615) 396-7476

We are inviting you to participate because you are a woman age 65 years or older, who underwent surgery for breast cancer and participated in the parent study, NR016695: "The Genomic Underpinnings for Breast Cancer Treatment-Induced Nausea." We anticipate recruiting approximately 30 women for participation in the current study.

The goal of this study is to learn more about things that might keep patients with cancer from having the best possible control of their pain. It is our hope to find out more about how patients with cancer communicate with their doctors, nurses, and other healthcare providers. With this knowledge, we plan to evaluate this communication process and determine whether improvements are needed. With your permission, we would like to use some of the data we collected during your participation in the parent study. This would include information about your race, type of surgery, pain scores, medications and dosages, methods used to relieve pain (example: applying ice to the site of the pain), and your answers to survey questions during the parent study. Please be aware that all members of this study's team are also members of the research team for the parent study.

The study will be conducted as follows:

1. We will ask you between five and six questions via telephone. Our interview questions will focus on your experiences with pain management, including how you treat your pain, your thoughts on pain management methods, and communicating with your cancer team about pain. We ask that you give as complete answers to questions as possible and to speak clearly so that the recording device will pick up your voice. Please speak freely, as the answers to your questions will be assigned a code known only to members of the research study and kept confidential.

2. The interview is expected to last anywhere from 45 minutes to one-and-a-half hours. In appreciation for completing the interview, we will add $25 to your Vincent card for you to spend as you choose to thank you for your participation.

3. We will only contact you again regarding this interview if any problems arise with the transcription of your interview or to clarify any points we may not have understood.

4. Your interview will be recorded and transcribed. The research team will then look for themes throughout your transcript and compare these with the themes found in other participants' interviews. The results will then be compiled, and a manuscript will be written that shares the findings to inform future research.

What are the possible risks, side effects, and discomforts of this research study?
Risks of study measures
It is possible that, during the course of the interview, you may become frustrated or tired. In order to prevent feeling tired, you are allowed to take breaks during the interview. Please keep in mind that participation is voluntary, so you are not required to answer questions unless you choose to do so.
Risks of privacy and breach of confidentiality
There is a possibility that your study research data could become generally known; however, all data will be identified by a code and will not contain identifying information, such as your name or birthdate.

What are possible benefits from taking part in this study?
There is the very little potential for direct benefit from participation in this study. However, our hope is that the lessons learned from this research study will help us design future research to increase women's ability to achieve adequate pain control.

What treatments or procedures are available if I decide not to take part in this research study?
Because this study does not involve any type of medical treatment, no treatments or procedures are available if you decide not to take part in this research study.

To protect your privacy and maintain confidentiality of information we obtain from you, we will keep all information about you in a secure location. All paper records that could identify you will be stored in locked file cabinets kept in a locked office. Transcribed interviews will be stored on password-protected file servers that require double authentication to access. Your identity on these records will be indicated by an assigned code number. The code linking your name to this number will be maintained separately with very limited access to research team members. In future, identifiers may be removed from your identifiable private information, and, following removal of this identifiable information, the information you provided might possibly be used for future research studies or distributed to another investigator for future research studies without additional informed consent from you or your legally authorized representative.

Upon completion of the interview, you will be paid $25.00 for taking part in this study.

Your participation in this research study is completely voluntary. Whether or not you participate will have no effect on your current or future relationship with the University of Pittsburgh or Magee Women's Hospital, its affiliated health care providers, health insurance providers, or any other studies in which you are a participant. If you decide you no longer wish to participate after you have signed the consent form, you should contact Karen Alsbrook at 615-396-7476. You may also withdraw from the study at any time. Should you choose to do so, your interview will be deleted, and the information provided up to that point will not be utilized. Your decision to withdraw from this study will have no effect on your current or future relationship with the University of Pittsburgh or with UPMC or its affiliate health care and insurance providers.

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VOLUNTARY CONSENT

By verbally agreeing to participate, you declare that everything has been explained to you, and all of your current questions have been answered. You also understand that you are encouraged to ask questions about any aspect of this research during the course of this study, and such questions or any concerns should be addressed by the principal investigator, Karen Alsbrook. At any point, you

may also contact the Human Subject Protection Advocate of the IRB Office, University of Pittsburgh (1-866-212-2668) to discuss problems, concerns, and questions; to obtain information; to offer input; or to discuss situations in the event that the research team is unavailable. In order to ensure that your rights are being protected, the Office of Research Protections may have access to your data—this includes identifiable data for the purposes of monitoring this study. Please be advised that University of Pittsburgh policy requires that all research records be maintained for at least seven years following final reporting or publication of a project.

By giving your verbal consent, you agree to participate in this research study and authorize the use and disclosure of the information provided throughout the course of the interview as previously explained for the purposes already described. A copy of this consent form has been mailed to your home.

Appendix F First revision of interview guide for qualitative study

Talking Pain Interview Questions

Question: What have older women with breast cancer experienced when communicating about pain control?

Introduction: Hello, my name is (Karen). Today is (date), and the time is (time). The purpose of this research study is to explore the barriers to optimal cancer pain control for older women with breast cancer who have experienced pain by evaluating current communication practices to inform the changes that need to occur to facilitate communication with their cancer care teams. To serve this purpose, we will be interviewing study participants from the parent study, "Genomic Underpinnings for Breast Cancer Treatment-Induced Nausea and Vomiting," who are age 65 or older. If you are willing to participate, we would like your permission to use information collected in the parent study, such as your health history, medication lists, and demographics. Our interview questions will focus on your experiences with pain management, including how you treat your pain, your thoughts on pain management methods, and communicating with your cancer team about pain. The interview should last somewhere between 45 minutes and an hour and a half. There are no foreseeable risks associated with this project, nor are there any direct benefits to you. If we get through all the interview questions, we will add $25 to your Vincent card as a token of our appreciation. The data obtained from you during this interview will be coded to protect your identity. The recording and transcript will only contain the name by which you requested we call you throughout the course of the interview, and the written

transcript will be linked to your unique, assigned code, all of which will be kept on a password-protected laptop. Your participation is completely voluntary, meaning you may withdraw from this project at any time. This study is being conducted by Karen Alsbrook, who can be reached at (615) 396-7476, if you have any questions.

Please keep in mind that you are by no means required to answer every question, and you may stop the interview at any time you choose. Please let me know if you need a break, and we will stop the interview until such time that you feel comfortable to resume. We plan to use the information we obtain to help us to identify areas upon which improvements could be made in communication between patients with cancer and providers regarding pain control. This interview is being audio recorded to make sure we clearly understand your answers to the questions. Only members of our research team will have access to the audio-recorded interview. Please try your best to answer each question fully and to the best of your ability, but please keep in mind that you are not obligated to answer any questions that make you feel uncomfortable. Do you have any questions before we begin?

Domain of Interest	Interview Question
Icebreaker	For the purposes of this interview, may I call you (Mrs. Smith), or how would you prefer to be addressed? (Mrs. Smith), you have been chosen to participate because you are age 65 or older and have, at some point during your surveys for our TINV study, rated your pain at “4” or greater on a 0-10 scale.
Perceptions of pain management	Tell me how you have been managing your pain. (Probes: Do you take prescribed medications? Something over the counter? Apply ice/heat/pain-relieving ointment?) How well do these treatments work? (Probes: Does the pain get better/worse? Does it relieve the pain/make it manageable?)
Perceptions of pain management	Tell me how you have been managing your pain. (Probes: Do you take prescribed medications? Something over the counter? Apply ice/heat/pain-relieving ointment?) How well do these treatments work? (Probes: Does the pain get better/worse? Does it relieve the pain/make it manageable?)
Knowledge	Can you recall how you were instructed or otherwise prepared to take this medication (or perform this intervention, such as application of

Domain of Interest	Interview Question
	ice/heat) and the directions you were given?
Perceptions of pain management	Tell me about any circumstance in which your pain was not well-controlled and any difficulties you have experienced associated with pain. (Probe: Tell me more about that.)
Challenges associated with opioids	Using opioids to manage pain can sometimes be challenging—what are your thoughts on using opioids to manage pain? (Probe: Can you tell me more about that?)
Self-advocating for needs	How do you go about talking with your cancer team about your pain? (Probes: When your pain is not well-controlled, do you tell your cancer team about your pain?
Shared decision-making	Tell me about how you and your care team work together to plan for keeping your pain well-controlled. (Probe: What have you and your team decided to do if your pain is no longer under control?)
Perceptions of pain management	How would you describe your cancer team's responsiveness to your pain? (Probe: Describe any problems you have encountered with your cancer team regarding pain.)
Perceptions of pain management	Is there anything else you feel I should know about pain and your cancer team?
Conclusion	Thank you so very much for your time and participation in this study. As promised, we will be adding $25 to your Vincent card as a token of our appreciation.

Appendix G Second revision of interview guide for qualitative study

TALKING PAIN INTERVIEW SCRIPT

TO BE COMPLETED and RECORDED on the DAY of the INTERVIEW

Good (Morning/Afternoon/Evening). This is (Your Name) calling from the University of Pittsburgh. Is this (Participant's First Name)? (await response) How are you? (await response) I want to thank you again for helping us out with this study. We are hoping that we can learn more about things that might keep patients with cancer from having the best possible control of their pain and how they communicate with doctors, nurses, and other healthcare providers. I will be asking for your consent and making sure you understand what we will be doing today before we start the interview questions, if that's all right with you. Do you mind if I begin the recording? (wait for response)

(Start recording). This is (name of person obtaining consent). Today is (date) at (time). May I call you (Participant's first name)? (Participant's first name), do you fully understand and consent to participating in this study as explained in the consent form you received? (wait for response)

CERTIFICATION of INFORMED CONSENT

I, (name of person obtaining consent), (role in research study), have explained the nature and purpose of this research study to (name of interview participant), and she is aware of the potential benefits and possible risks of study participation. Any questions that (name of interview participant) has about this study have been answered, and we will always be available to address future questions as they arise. Other than data collected throughout the course of the parent study, no research component of this protocol was begun until after verbal consent was obtained.

(Name of interview participant), do you have any questions before we begin?

> ***Interviewer: Please adhere to the questions as closely as possible, employing the probes only when respondent is not forthcoming.***

Interview Question
(Participant's First Name), can you please tell me what you do to manage your pain? (Probes: Do you take prescribed medications? Something over the counter? Apply ice/heat/pain-relieving ointment?) How well do these treatments work? (Probes: Does the pain get better/worse? Does it relieve the pain/make it manageable?)
Do you remember if or how you were instructed or otherwise prepared to take this medication (or perform this intervention, such as application of ice/heat) and the directions you were given?
Can you tell me about a time your pain was not well-managed? (Probe: What difficulties have

Interview Question
you experienced associated with pain?)
Using opioids to manage pain can sometimes be challenging—what are your thoughts on using opioids to manage pain? (Probe: Can you tell me more about that?)
Do you have a cancer care team? (If yes: “Tell me about your relationship with your cancer care team.” If no, ask “When your pain is not well-controlled, who do you notify?” Then, refer to this person/persons instead of “cancer team/care team,” moving forward)
Tell me about how you and your care team work together to plan for keeping your pain well-controlled. (Probe: What have you and your cancer team decided to do if your pain is no longer under control?)
How would you describe your cancer team’s responsiveness to your pain? (Probe: Describe any problems you have encountered with your cancer team regarding pain.)
Is there anything else you feel I should know about pain and your cancer team?
Thank you so very much for your time and participation in this study. As promised, we will be adding $25 to your Vincent card as a token of our appreciation.

Appendix H Third revision of interview guide for qualitative study

TALKING PAIN INTERVIEW SCRIPT
(instructions in bold are not intended to be read aloud to interviewee)

TO BE COMPLETED and RECORDED on the DAY of the INTERVIEW *(please remember to speak slowly and clearly)*

Good (Morning/Afternoon/Evening). This is (Your Name) calling from Pitt School of Nursing. Is this (Participant's First Name)? (await response) How are you? (await response)

I want to thank you again for helping us out with this study. We hope that we can learn more about things that might keep patients with cancer from having the best possible control of their pain. We also want to understand how patients like you communicate with doctors, nurses, and other healthcare providers. Before we start, I will be asking for your consent to make sure you understand what we going to do today. Are you OK if I begin the recording? (wait for response)

(Start recording).

This is (name of person obtaining consent). Today is (date) at (time). May I call you (Participant's first name)? (Participant's first name), do you fully understand and consent to participating in this study as explained in the consent form you received? (wait for response)

CERTIFICATION of INFORMED CONSENT

I, (name of person obtaining consent), (role in research study), have confirmed that (name of interview participant) understands the nature and purpose of this research study and is aware of the potential benefits and possible risks of study participation. Any questions that (name of interview participant) has about this study have been answered, and we will always be available to address future questions as they arise. Other than data collected throughout the course of the parent study, no research component of this protocol was begun until after verbal consent was obtained.

(Name of interview participant), do you have any questions before we begin?

> ***Interviewer: Please adhere to the questions as closely as possible, employing the probes only when respondent is not forthcoming. "Tell me more about that" is always an acceptable probe also.***

Interview Question
(Participant's First Name), can you please tell me what all you have done and are doing to manage your pain? (Probes: Do you take prescribed pain medications? Do you take anything over the counter for pain? Do you ever apply ice/heat/pain-relieving cream?) How well do these treatments work? (Probes: Does the pain get better/worse? Does it relieve the pain/make it manageable?)
Do you remember if or how you were instructed or otherwise prepared to take this medication (or perform this intervention, such as application of ice/heat) and the directions you were given? (Probe: When you were sent home after your surgery, for example, how were instructions for relieving your pain given to you?)
Can you tell me about a time your pain was not well-managed? (Probes: If you don't take medications to relieve your pain, what do you do to cope with the pain? What difficulties have you experienced associated with pain?)
What are your thoughts about using opioid pain medications like tramadol, hydrocodone, oxycodone, Dilaudid, codeine, and morphine to manage pain?
Do you have a team of doctors, nurses, nurse practitioners, physician assistants responsible for your cancer care? **(If yes: "Tell me about your relationship with your cancer care team." If no, ask "When your pain is not well-controlled, who do you notify?" Then, refer to this person/persons instead of "cancer team/care team," moving forward)**
Tell me about how you and your care team work together to plan for keeping your pain well-controlled. (Probe: What have you and your cancer team decided to do when you have pain?)
How would you describe your cancer team's responsiveness to your pain needs? (Probe: Describe any problems you have encountered with your cancer team regarding pain.)
Is there anything else you feel I should know about pain and your cancer team?
Thank you so very much for your time and participation in this study. As promised, we will be adding $25 to your Vincent card as a token of our appreciation.

Appendix I Final revision of interview guide for qualitative study

TALKING PAIN INTERVIEW SCRIPT
(instructions in bold are not intended to be read aloud to interviewee)

TO BE COMPLETED and RECORDED on the DAY of the INTERVIEW *(please remember to speak slowly and clearly)*

Good (Morning/Afternoon/Evening). This is (Your Name) calling from Pitt School of Nursing. Is this (Participant's First Name)? (await response) How are you? (await response)

Did you have an opportunity to review the consent form we sent? (go over consent form with them, if not). Do you have any questions or concerns about what you read before we begin? (wait for response)

OK, (Participant's First Name), just so you know, I will be asking for your verbal consent as soon as we begin recording to verify that you understand what we going to do today. Are you OK if I begin the recording? (wait for response)

(Start recording).

This is (name of person obtaining consent). Today is (date) at (time). May I call you (Participant's first name)? (Participant's first name), do you fully understand and consent to participating in this study as explained in the consent form you received? (wait for response)

CERTIFICATION of INFORMED CONSENT

I, (name of person obtaining consent), (role in research study), have confirmed that (name of interview participant) understands the nature and purpose of this research study and is aware of the potential benefits and possible risks of study participation. Any questions that (name of interview participant) has about this study have been answered, and we will always be available to address future questions as they arise. Other than data collected throughout the course of the parent study, no research component of this protocol was begun until after verbal consent was obtained.

(Name of interview participant), do you have any questions before we begin?

> ***Interviewer: Please adhere to the questions as closely as possible, employing the probes only when respondent is not forthcoming. "Tell me more about that" is always an acceptable probe also.***

Interview Question
I want to thank you again for helping us out with this study. We hope that we can learn more about things that might keep patients with cancer from having the best possible control of their pain. We also want to understand how patients like you communicate with doctors, nurses, and other healthcare providers. It is so valuable for us to learn more about the experiences of women with cancer who are 65 or older and their experiences with pain management. We have a series of questions that we hope to cover, but please feel free to elaborate or add comments at any time. Also, feel free to pause and think about the question being asked or ask me to clarify anything I ask that is unclear. **(Participant's First Name), do you have any questions before we begin?** **(Participant's First Name), can you please tell me about your experiences with physical pain, starting with anything that you might remember before your breast surgery, the time around your breast surgery, and moving to the present?** (Probes: May need to remind them of the timeframe about which you are speaking and ask them to tell you more) **(Participant's First Name), what all have you done in the past, and what are you currently doing to manage your pain?** (Probes: Do you take prescribed pain medications? Do you take anything over the counter for pain? Do you ever apply ice/heat/pain-relieving cream? How well do these treatments work? Does the pain get better/worse? Does it relieve the pain/make it manageable?)
Do you remember if or how you were instructed or otherwise prepared to take this medication (or perform this intervention, such as application of ice/heat) and the directions you were given? (Probe: When you were sent home after your surgery, for example, how were instructions for relieving your pain given to you?)
Can you describe for me whether the pain you experienced during and after your procedures was more, less than, or as you expected and why? (Probe: in other words, did you think you would be in more pain than you actually were, or what was your experience?) **What are your thoughts about using opioid pain medications like tramadol, hydrocodone, oxycodone, Dilaudid, codeine, and morphine to manage pain, for yourself and for others in general?**
Can you tell me about a time your pain was not well-managed? (Probes: If you don't take medications to relieve your pain, what do you do to cope with the pain? What difficulties have you experienced associated with pain?)
"Have you ever reported your pain to anyone? If so, who? PCP? Oncologist? Other? **Do you have a team of doctors, nurses, nurse practitioners, physician assistants respon-**

Interview Question
sible for your cancer care? (If yes: "Tell me about your relationship with your cancer care team." If no, ask "When your pain is not well-controlled, who do you notify?" Then, refer to this person/persons instead of "cancer team/care team," moving forward)
Tell me about how you and your care team work together to plan for keeping your pain well-controlled. (Probe: What have you and your cancer team decided to do when you have pain?)
How would you describe your cancer team's responsiveness to your pain needs? (Probe: Describe any problems you have encountered with your cancer team regarding pain.)
Is there anything else you feel I should know about pain and your cancer team?
Thank you so very much for your time and participation in this study, (participant's first name). As promised, we will be adding $25 to your Vincent card as a token of our appreciation.

Appendix J Initial draft of codebook

Code	Description
adverse effects_Aleve	Experienced or fears adverse effects from naproxen sodium
adverse effects_Motrin/Advil	Experienced or fears adverse effects from ibuprofen
adverse effects_opioids	Experienced or fears adverse effects from opioids
adverse effects_pain	Experienced adverse effects from pain other than pain itself
adverse effects_Tylenol	Experienced or fears adverse effects from acetaminophen
advocate_PCP	Relies on, reaches out to PCP for care
careteam_call_no	Does not call care team for help
careteam_call_no_self-manage	Does not call care team for help - handles problems independent of care team
careteam_call_yes	Calls care team for help
careteam_disconnect	Does not interact with careteam
careteam_no	Does not have a care team
careteam_yes	Has a care team
careteam_pain_negative	Experienced negative interaction with care team about pain management
careteam_pain_no	Did not reach out to care team when experienced unmanaged pain
careteam_pain_positive	Experiences with addressing pain management with care team are positive
careteam_pain_yes	Reached out to care team when experienced unmanaged pain
careteam_pain concerns_no	Does not feel comfortable reaching out to care team for unmanaged pain
careteam_pain concerns_yes	Feels comfortable reaching out to care team for unmanaged pain
careteam_pain intervention_testing	Cancer care team intervened by testing when pain reported
careteam_PCP_no	Cancer care team does not communicate with PCP
careteam_PCP_unsure	Unsure whether cancer care team communicates with PCP
careteam_PCP_yes	Cancer care team communicates with PCP
careteam_relationship_negative	Negative opinions regarding her cancer care team
careteam_relationship_positive	Advocates a positive working relationship with her cancer care team
instructions_heat	Instructed to employ the application of heat to assist with pain relief
instructions_ice	Instructed to employ the application of ice to assist with pain relief
opioid opinion_acute pain only	Verbalized that opioid use should be reserved for postoperative/acute pain only
opioid opinion_addiction	Verbalized that employing opioid analgesia places one at risk for addiction
opioid opinion_dissonance	Verbalized that opioids are to be avoided yet medical record or dialogue indicates otherwise
opioid opinion_overmedicated	Avoids taking opioid analgesia because of high medication burden
opioid opinion_palliative	Believes opioids should be reserved for palliative care only
opioid opinion_positive	Advocates the use of opioid analgesia as needed
opioid opinion_self_no	Expressed that she chooses not to ever employ opioids for pain management
opioid opinion_sideeffects	Avoids employing opioid analgesia due to fear of side effects
opioid opinion_unknown	Avoids employing opioid analgesia for unknown reasons
pain_acceptance	Perceives pain to be an unavoidable constant
pain_advanced age	Attributes pain to old age/normal part of aging process

pain_arthritic	Pain is described as joint pain/arthritic in nature
pain_high tolerance	Describes self as being able to tolerate severe pain
pain_managed	Feels pain is well-managed
pain_musculoskeletal	Pain is described as a bone or muscle ache or pain
pain_neuropathic	Pain is described as neuropathic in nature
pain_point of contact	Able to identify the provider responsible for management of pain
pain_postoperative_no	Endorses being in pain immediately following breast surgery
pain_postoperative_yes	Denies being in pain immediately following breast surgery
pain_recurrent	Pain returned after analgesic measure enacted
pain_self advocacy	Took an action to advocate for pain needs (e.g., reported adverse reaction)
pain_tough it out	Actively made choice not to intervene to manage pain
pain_unmanaged	Experienced at least one incident of unmanaged pain
pain_unmanaged_obstacles	Identifies one or more obstacles to management of pain
pain_well-managed_no	Cannot recall a time when pain was not well-managed
pain_well-managed_yes	Able to recall a time when pain was not well-managed
pain plan_convoluted	Unsure whether a pain plan has ever been created for her or her pain plan is vague
pain plan_no	Has no pain management plan established with cancer care team
pain plan_self	Devised and employs own pain management plan (non-collaborative)
pain plan_yes	Established a pain management plan with cancer care team
pain relief_alternative_chiropractor	Has consulted with chiropractor for pain issues
pain relief_alternative_exercise	Exercise employed for pain relief
pain relief_alternative_heat	Heat employed for pain relief
pain relief_alternative_ice	Ice employed for pain relief
pain relief_alternative_none	No alternative therapies employed for pain relief
pain relief_alternative_PT	Physical therapy employed as pain relief modality
pain relief_alternative_topicals	Topicals employed for pain relief (Lidoderm patches, SalonPas, Aspercreme)
pain relief_Aleve	Naproxen sodium employed for pain relief
pain relief_Motrin/Advil	Ibuprofen employed for pain relief
pain relief_opioid	Opioid analgesia employed for pain relief
pain relief_opinion_overmedicated	Avoids all forms of analgesia due to "medication fatigue"
pain relief_schedule	How often analgesia taken
pain relief_steroid injection	Receives steroid injections for pain relief
pain relief_time	Amount of time it takes to achieve pain relief
pain relief_Tylenol	Acetaminophen employed for pain relief
prescription_no	Did not receive a prescription for opioid analgesia at time of discharge
prescription_no_not needed	Does not have prescribed opioid analgesia because it was unnecessary

Appendix K Final draft of codebook

Codes	Description of Code
careteam_call_no	Denies ever calling careteam for assistance, reasons not given
careteam_call_yes	Calls careteam for help
careteam_disconnect	Does not interact with careteam
careteam_fragmented care	Does not consistently see same provider/work with same careteam
careteam_pain concerns_no	Does not feel comfortable reaching out to care-team for unmanaged pain
careteam_pain concerns_yes	Feels comfortable reaching out to careteam for unmanaged pain
careteam_pain_negative	Experienced negative interaction with careteam about pain management
careteam_pain_no	Did not reach out to careteam when experienced unmanaged pain
careteam_pain_positive	Experiences with addressing pain management with careteam are positive
careteam_pain_yes	Reached out to careteam when experienced un-managed pain
careteam_PCP_yes	Cancer careteam communicates with PCP (im-portant due to transition to survivorship)
careteam_point of contact_no	Unable to identify with whom to communicate re-garding unmet needs
careteam_point of contact_yes	Identifies member of careteam with whom needs are to be communicated
careteam_relationship_negative	Negative opinions regarding her cancer careteam
careteam_relationship_positive	Advocates a positive working relationship with her cancer careteam
careteam_relies on PCP	Reaches out to PCP for concerns/desire to avoid specialists
careteam_unclear	Considers providers the careteam/unsure of what constitutes a multidisciplinary careteam
careteam_yes	Has a careteam
opinion_opioids_acute pain only	Verbalized that opioid use should be reserved for postoperative/acute pain
opinion_opioids_addiction	Verbalized that employing opioid analgesia places one at risk for addiction

Codes	Description of Code
opinion_opioids_dire situations only	Verbalized that opioid use should be reserved as last resort for managing pain
opinion_opioids_dissonance	Verbalized that opioids are to be avoided yet endorses having employed opioid analgesia
opinion_opioids_evasion	Exhibited signs of discomfort with the topic of opioids (e.g., interrupted interviewer)
opinion_opioids_ineffective	Avoids employing opioid analgesia because perceived as ineffective
opinion_opioids_negative	Expressed a negative opinion of opioid analgesia
opinion_opioids_end of life	Believes opioids should be reserved for end of life/terminal illness only
opinion_opioids_patient discretion	Believes need for opioids should be determined by the patient
opinion_opioids_positive	Advocates the use of opioid analgesia as needed
opinion_opioids_provider discretion	Believes opioids should be employed at the discretion of the prescribing provider
opinion_opioids_self_no	Expressed that she chooses not to ever employ opioids for pain management
opinion_opioids_side effects	Avoids employing opioid analgesia due to fear of side effects
opinion_opioids_unknown	Avoids employing opioid analgesia for unknown reasons
pain mgmt_barriers_acceptance	Accepts undermanaged pain due to various reasons (e.g., normalized to older adults, cancer)
pain mgmt_barriers_chronic illness	Pain attributed to chronic illness other than cancer (e.g., rheumatoid arthritis)
pain mgmt_barriers_dislikes taking medication	Avoids analgesics due to dislike of medications/desire to avoid taking more medications
pain mgmt_barriers_external	Attributes undermanaged pain to an external factor (e.g., cold air causing joints to ache)
pain mgmt_barriers_hopelessness	Has stopped pursuing better pain management thinking there is no solution
pain mgmt_barriers_lack of information	Did not/does not manage pain optimally due to lack of knowledge of pain/pain management
pain mgmt_barriers_lack of support	Feels that pain would be better managed with support from others
pain mgmt_barriers_noncompliance	Attributes pain to nonadherence to provider recommendations (e.g., avoiding exercises)
pain mgmt_barriers_physical condition	Attributes non-optimal pain management to physical problem (e.g., HTN prevents injections)
pain mgmt_barriers_psychological distress	Psychological distress impaired optimal pain management
pain mgmt_barriers_reluctance_opiophobia	Expressed reluctance to employ opioid pain management due to fear of opioid addiction/AEs
pain mgmt_barriers_reluctance_provider	Provider reluctant to treat pain due to its subjectiv-

Codes	Description of Code
	ity (e.g., x-ray shows no cause of pain)
pain mgmt_barriers_SUD	Pain not optimally managed due previous substance use disorder
pain mgmt_facilitators_paces self	Manages pain threshold by pacing activity
pain mgmt_facilitators_perioperative pain management	Well-managed perioperative pain results in optimal outcomes
pain mgmt_facilitators_resilience_high tolerance	Describes self as one who has a high tolerance for pain
pain mgmt_facilitators_resilience_meaning	Expressed a desire to make meaning of cancer experience (venting, helping others)
pain mgmt_facilitators_resilience_positive attitude	Advocates/answers indicative of a positive attitude
pain mgmt_facilitators_resilience_provide support	Endorses giving support to a fellow patient with cancer
pain mgmt_facilitators_resilience_receive support	Endorses receiving support from others
pain mgmt_facilitators_resilience_self-advocacy	Advocated for own needs/desires
pain mgmt_factors_external influences	Pain management practices derived from non-professional influences (e.g., family, friends)
pain mgmt_factors_internal influences	Pain management practices influenced by own perceptions (e.g., life experiences, beliefs)
pain mgmt_factors_psychological	Psychological factors are cause or consequence of pain
pain mgmt_factors_treatment_aromatase inhibitor	Attributes pain to effects of aromatase inhibitor
pain mgmt_factors_treatment_chemotherapy	Attributes pain to effects of chemotherapy
pain mgmt_factors_treatment_radiation	Attributes pain to effects of radiation
pain mgmt_factors_treatment_surgery	Attributes pain to effects of cancer surgery (e.g., lymphedema)
pain mgmt_nonpharm_alternative	Employed nontraditional pain management (e.g., CBD, chiropractor, dietary changes)
pain mgmt_nonpharm_no	No alternative therapies employed for pain management
pain mgmt_nonpharm_physical	employed physical pain management (e.g., PT, supportive device, exercise)
pain mgmt_nonpharm_topical	Topicals employed for pain relief (ice, heat, Lidoderm patches, Salonpas, Aspercreme)
pain mgmt_pharm_acetaminophen	Acetaminophen employed for pain relief
pain mgmt_pharm_adverse effects_acetaminophen	Experienced or fears adverse effects from acetaminophen
pain mgmt_pharm_adverse effects_gabapentin	Experienced or fears adverse effects from gabapentin
pain mgmt_pharm_adverse effects_muscle relaxer	Experienced or fears adverse effects from muscle relaxers

Codes	Description of Code
pain mgmt_pharm_adverse effects_NSAIDs	Experienced or fears adverse effects from NSAIDs
pain mgmt_pharm_adverse effects_opioids	Experienced or fears adverse effects from opioids
pain mgmt_pharm_contraindicated_acetaminophen	Has physical condition for which acetaminophen is contraindicated (e.g., liver disease)
pain mgmt_pharm_contraindicated_NSAIDs	Has physical condition for which NSAIDs are contra-indicated (e.g., kidney disease)
pain mgmt_pharm_contraindicated_opioids	Opioid analgesia is contraindicated (e.g., allergy, prior adverse reaction)
pain mgmt_pharm_Euflexxa injection	Euflexxa injected into joints for pain relief
pain mgmt_pharm_neuromuscular	prescribed analgesia that targets nerve or muscle pain (e.g., gabapentin, muscle relaxers)
pain mgmt_pharm_NSAID	Muscle relaxer prescribed for pain management
pain mgmt_pharm_opioid	NSAIDS employed for pain management
pain mgmt_pharm_steroids	Opioid analgesia employed for pain relief
pain mgmt_timing	Receives steroids for pain management, either in-jections or oral
pain plan_no	Has no pain management plan established with cancer careteam
pain plan_unclear	Unsure whether a pain plan has ever been created for her or her pain plan is vague
pain plan_yes	Established a pain management plan with cancer careteam
pain_chronic_arthritic	Pain is described as joint pain/arthritic in nature
pain_chronic_breast-related	Continues to experience breast-related pain alt-hough initial surgery was over one year ago
pain_chronic_musculoskeletal	Pain is described as a bone or muscle ache or pain
pain_chronic_neuropathic	Pain is described as neuropathic in nature
pain_concurrent physical distress	Experienced adverse effects from the pain itself (e.g., nausea, SOB)
pain_inconsistent reporting	Denies experiencing pain yet meets inclusion crite-ria for study participation
pain_postoperative_no	Denies being in pain immediately following breast surgery
pain_postoperative_yes	Endorses being in pain immediately following breast surgery
pain_recurrent	Pain returned after analgesic measure enacted
pain_self advocacy	Took an action to advocate for pain needs (e.g., reported adverse reaction)
pain_tough it out	Actively made choice not to intervene to manage pain
pain_undermanaged_no	Cannot recall a time when pain was not well-managed
pain_undermanaged_yes	Able to recall a time when pain was not well-managed

Codes	Description of Code
pain_undermanaged_yes_consequences	Persistent pain detrimental physically and/or psychologically
prescription education_no	Does not recall receiving education regarding analgesia at time of discharge
prescription education_verbal	Received verbal prescription education at time of hospital discharge
prescription education_written	Received written prescription education at time of hospital discharge
prescription education_yes	Received prescription education at time of hospital discharge
prescription_no	Does not recall receiving education regarding analgesia at time of discharge
prescription_yes	Received a prescription for opioid analgesia at time of discharge, unknown whether used
prescription_yes_unused	Received but did not use prescribed opioid analgesia after hospital discharge
prescription_yes_used	Received and used prescribed opioid analgesia after hospital discharge
prescription education_unsure	Unsure whether received prescription education at time of hospital discharge
TOTAL CODES: 109	

Appendix L Consolidated criteria for reporting qualitative research (COREQ) guidelines

No.	Item	Guide questions/description
Domain 1: Research team and reflexivity		
Personal Characteristics		
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group? **All interviews: K.A. (18); S.P. (2), C.H. (1)**
2.	Credentials	What were the researcher's credentials? *E.g. PhD, MD* **K.A. (BSN, OCN, PhD Student); S.P. and E.K. (BS); C.H. (MPH)**
3.	Occupation	What was their occupation at the time of the study? **K.A. (RN/graduate student researcher); S.P. and E.K. (research assistant/recruiter); C.H. (project manager of parent study); Y.Z. (undergraduate nursing student/research program mentee)**
4.	Gender	Was the researcher male or female? **all researchers were female.**
5.	Experience and training	What experience or training did the re-

No.	Item	Guide questions/description
		searcher have? **K.A.: 20+ years as nurse, 3+ years as graduate student researcher, completed 2 courses on qualitative research and 1 course on qualitative/MM research; C.H.: 2+ years as researcher, 1+ years as project manager for parent study, and multiple courses in research methodologies; S.P. and E.K.: 1+ years as research assistants/recruiters for parent study.**
Relationship with participants		
6.	Relationship established	Was a relationship established prior to study commencement? **yes**
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? e*.g. personal goals, reasons for doing the research* → **Participants were aware that all three interviewers (C.H., K.A., and S.P.) were researchers for the parent study.**
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. *Bias, assumptions, reasons and interests in the research topic.* **Participants were reminded that the interviewers were also researchers for the parent study and that the principal investigator (K.A.) is an oncology nurse and PhD student interested in the pain experiences of women with breast cancer who are aged 65 and older.**
Domain 2:		

No.	Item	Guide questions/description
study design		
Theoretical framework		
9.	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? (*e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis)* **qualitative description**
Participant selection		
10.	Sampling	How were participants selected? *e.g. purposive, convenience, consecutive, snowball* **1. criterion-based case selection, 2. purposive sampling, 3. reputational case selection**
11.	Method of approach	How were participants approached? e*.g. face-to-face, telephone, mail, email?* **per choice in parent study: telephone or email.**
12.	Sample size	How many participants were in the study? **n=21**
13.	Non-participation	How many people refused to participate or dropped out? **3 refused, 3 dropped out.** Reasons? **1. "it would take too long;" 2. recent knee replacement; 3. spinal stenosis and peripheral neuropathy. One dropped out before proceeding with the interview after being informed that her interview would be recorded; another dropped out due to her husband's acute critical illness; and a third who was un-**

No.	Item	Guide questions/description
		dergoing treatment for liver metastases.
Setting		
14.	Setting of data collection	Where was the data collected? e*.g. home, clinic, workplace* **Data were collected via telephone in location of participant's own choosing (usually home).**
15.	Presence of non-participants	Was anyone else present besides the participants and researchers? **No one disclosed that any other individuals were present during the interviews.**
16.	Description of sample	What are the important characteristics of the sample? *e.g. demographic data, date* **The sample consists of seven Black and 14 White women aged 65 and older as of March 1, 2021 who underwent surgery for breast cancer, participated in the parent study, and reported a pain level of 4/10 or greater at least once during study participation.**
Data collection		
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested? **Interview guides are provided and were pilot-tested prior to implementation.**
18.	Repeat interviews	Were repeat interviews carried out? **No.** If yes, how many?
19.	Audio/visual recording	Did the research use audio or visual recording to collect the data? **Laptop micro-**

No.	Item	Guide questions/description
		phones were used for audio recording.
20.	Field notes	Were field notes made during and/or after the interview or focus group? **Memos were made during and after each interview.**
21.	Duration	What was the duration of the interviews or focus group? **Interviews ranged from 6 minutes to 1 hour.**
22.	Data saturation	Was data saturation discussed? **yes, and reached at n=21.**
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction? **no**
Domain 3: analysis and findings		
Data analysis		
24.	Number of data coders	How many data coders coded the data? **three**
25.	Description of the coding tree	Did authors provide a description of the coding tree? **yes—spreadsheet of codes with descriptions for each provided. Each iteration of the codebook has been archived.**
26.	Derivation of themes	Were themes identified in advance or derived from the data? **themes emerged from the data during qualitative analyses.**
27.	Software	What software, if applicable, was used to

No.	Item	Guide questions/description
		manage the data? **NVivo 12 QDA Software**
28.	Participant checking	Did participants provide feedback on the findings? **No—emergent themes will be justified by direct quotations from participant transcripts.**
Reporting		
29.	Quotations presented	Were participant quotations presented to illustrate the themes / findings? **Yes.** Was each quotation identified? e*.g. participant number* **Quotes were identified by participant number in NVivo, but not in reporting results.**
30.	Data and findings consistent	Was there consistency between the data presented and the findings? **Yes.**
31.	Clarity of major themes	Were major themes clearly presented in the findings? **Yes.**
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes? **All codes were classified under themes and percentages of participants with coded responses to each were calculated.**

Appendix M IRB approval for quantitative study

University of Pittsburgh | Institutional Review Board
Office of Research Protections

APPROVAL OF SUBMISSION (Expedited)

Date:	May 12, 2022
IRB:	STUDY22010102
PI:	Karen Alsbrook
Title:	Factors Affecting Pain Reporting in Older Women with Breast Cancer

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:	5/12/2022
Expiration Date:	
Expedited Category	(7)(b) Social science methods, (7)(a) Behavioral research
Determinations:	• Waiver of consent documentation
Approved Documents:	• Combined Instruments for Data Collection • Bibliography Page for Works Cited Throughout Proposal • Consent to Participate • Email Recruiting Letter • FAPR Verbal Consent 5.10.22.docx • Recruiting Letter to Be Mailed • Telephone Script for Recruitment

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/.

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, Emily Bird.

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

Appendix N IRB approval for modification to quantitative study

University of Pittsburgh | Institutional Review Board
Office of Research Protections

APPROVAL OF SUBMISSION (Expedited)

Date:	July 6, 2022
IRB:	MOD22010102-001
PI:	Karen Alsbrook
Title:	Factors Affecting Pain Reporting in Older Women with Breast Cancer
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:	Modification / Update
Approval Date:	7/6/2022
Expedited Category	(7)(b) Social science methods, (7)(a) Behavioral research
Approved Documents:	• Email Recruiting Letter, 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/.

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, John Ries.

Please take a moment to complete our Satisfaction Survey as we appreciate your feedback. Human Research Protection Office 3500 Fifth Avenue, Suite 106 Pittsburgh, PA 15213 www.hrpo.pitt.edu

Appendix O Instruction letter for quantitative study

Dear [Participant Name],

Thank you so much for your participation in the Treatment-Induced Nausea and Vomiting (TINV) study. My name is Karen Alsbrook, and I am a doctoral student at the University of Pittsburgh School of Nursing. I am conducting a questionnaire study as part of my dissertation work to gain a better understanding of how older women with breast cancer communicate with their careteam; perceive pain management practices; and advocate for their healthcare needs. I would greatly appreciate your input via completion of the enclosed questionnaire.

There will be no benefit to your participation in this study. Your participation is completely voluntary, and you have the option to withdraw at any time.

Please be advised that a breach of confidentiality is possible in the data collection process. However, all measures will be taken to ensure that your privacy will be protected. Your name and personal information will not be associated with any study data and will be kept in a separate location.

First, please review and sign the consent form included with this mailing. The signed consent form must be returned along with the completed questionnaire in order for your data to be included in the study. You will receive a copy of the signed consent form for your records as well as a $20 addition to the balance on your Vincent card to spend however you choose as thanks for completing the questionnaire.

As a study participant, please be advised that:

- Participation in the study involves completion of the enclosed questionnaire; reading and signing the enclosed consent form; and returning both in the enclosed prepaid envelope. PLEASE DO NOT ADD YOUR RETURN ADDRESS TO THE RETURN ENVELOPE.
- Some of the questions asked may be considered sensitive, such as range of family income and your opinions regarding pain medications.
- This questionnaire should take less than 30 minutes to complete. Please feel free to take breaks, and return to its completion as needed, if you experience fatigue.

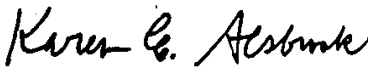
- With your consent, I would like to include data collected from you during participation throughout the TINV study in the statistical analyses for this study.
- Your participation in this research study may help us increase our understanding of how older women with breast cancer manage their pain and get their pain management needs met.

After I receive your signed consent form and completed questionnaire, I will add $20 to your Vincent card balance and send you a copy of your signed consent form.

Please note that your responses to this questionnaire will not be sent to your healthcare providers. If you have any questions or concerns about managing your pain or communicating with your care team, please reach out to them.

Thank you again for considering participation. If you have any questions, please contact me at kea64@pitt.edu.

Sincerely,



Karen E. Alsbrook, BSN, RN, OCN, PhD Student
University of Pittsburgh School of Nursing
440 Victoria Building
3500 Victoria Street
Pittsburgh, PA 15261

Appendix P Consent form for quantitative study

CONSENT TO ACT AS A PARTICIPANT IN A RESEARCH STUDY

TITLE: Factors Affecting Pain Reporting in Older Women with Breast Cancer

PRINCIPAL INVESTIGATOR: Karen Alsbrook, BSN, RN, OCN, PhD Student
kea64@pitt.edu
phone: (615) 396-7476

We are inviting you to participate because you are a woman aged 65 years or older, who underwent surgery for breast cancer and participated in the parent study, NR016695: "The Genomic Underpinnings for Breast Cancer Treatment-Induced Nausea." We anticipate recruiting approximately 75 women for participation in this study.

The goal of this study is to gain a better understanding of the factors that affect the pain management and pain reporting practices of older women with breast cancer. With the knowledge gained, it is our hope that we can identify ways in which to empower patients with cancer to get their pain management needs met. With your permission, we would like to use some of the data we collected during your participation in the parent study. This would include information about where you live as well as your age, race/ethnicity, type of surgery, pain scores, and answers to survey questions during your participation in the parent study. Please be aware that all members of this study's team are also members of the research team for the parent study.

The study will be conducted as follows:

1. We will send you either an electronic or paper version (your choice) of a 39-item questionnaire with questions about how you get your healthcare needs met; the flow of communication between you and your cancer care team; your opinions about treating pain with opioid (narcotic) pain medication; and level of education and income.
2. The questionnaire is expected to take no more than 30 minutes to complete.

Once we receive your signed consent form and completed questionnaire, we will mail you a copy of the signed consent form and add $20 to your Vincent card for you to spend as you choose as thanks for your participation.

3. We will only contact you again regarding this questionnaire if any problems arise or to fill in any unclear or missing information.
4. The answers to the questionnaire and data from the parent study mentioned above will be entered into a statistical software program to analyze the data, and the results will be included in a manuscript that shares our findings to inform future research.

What are the possible risks, side effects, and discomforts of this research study?

Risks of study measures

It is possible that, during questionnaire completion, you may become frustrated or tired. To prevent this from occurring, you are allowed to take breaks while completing the questionnaire. Please keep in mind that participation is voluntary, so you are not required to answer any of the questions unless you choose to do so.

Risks of privacy and breach of confidentiality

There is a possibility that your study research data could become generally known; however, all data will be identified by a code and will not contain identifying information, such as your name or birthdate.

What are possible benefits from taking part in this study?

There is the very little potential for direct benefit from participation in this study. However, our hope is that the lessons learned from this research study will help us design future research to increase the ability of patients with cancer to better manage their pain.

What treatments or procedures are available if I decide not to take part in this research study?

Because this study does not involve any type of medical treatment, no treatments or procedures are available if you decide not to take part in this research study.

To protect your privacy and maintain confidentiality of information we obtain from you, we will keep all information about you in a secure location. All paper records that could identify you will be stored in locked file cabinets kept in a locked office. Completed questionnaires and the data they contain will be stored on password-protected file servers that require double authentication to access. Your identity on these records will be indicated by an assigned code number. The code linking your name to this number will be maintained separately with very limited access to research team members. In future, identifiers may be removed from your identifiable private information, and, following removal of this identifiable information, the information you provided might possibly be used for future research studies or distributed to another investigator for future research studies without additional informed consent from you or your legally authorized representative.

Upon completion of the interview, you will be paid $20.00 for taking part in this study.

Your participation in this research study is completely voluntary. Whether or not you participate will have **no effect** on your current or future relationship with the University of Pittsburgh or Magee Women's Hospital, its affiliated health care providers, health insurance providers, or any other studies in which you are a participant. If you decide you no longer wish to participate after you have signed the consent form, you should contact Karen Alsbrook at 615-396-7476. You may also withdraw from the study at any time. Should you choose to do so, the information provided up to that point will not be utilized, and we will not include any of your data from the parent study in our analyses. Your decision to withdraw from this study will have **no effect** on your current or future relationship with the University of Pittsburgh or with UPMC or its affiliate health care and insurance providers.

****

VOLUNTARY CONSENT

By verbally agreeing to participate, you declare that everything has been explained to you, and all of your current questions have been answered. You also understand that you are encouraged to ask questions about any aspect of this research during the course of this study, and such questions or any concerns should be addressed by the principal investigator, Karen Alsbrook. At any point, you may also contact the Human Subject Protection Advocate of the IRB Office, University of Pittsburgh (1-866-212-2668) to discuss problems, concerns, and questions; to obtain information; to offer input; or to discuss situations in the event that the research team is unavailable. In order to ensure that your rights are being protected, the Office of Research Protections may have access to your data—this includes identifiable data for the purposes of monitoring this study. Please be advised that University of Pittsburgh policy requires that all research records be maintained for at least seven years following final reporting or publication of a project.

Your signature below indicates that you agree to participate in this research study and authorize the use and disclosure of the information you provide as previously explained for the purposes already described. A signed copy of this consent form will be mailed to the address you have indicated.

_____ _____

Participant's Signature Date

CERTIFICATION of INFORMED CONSENT

I certify that I have explained the nature and purpose of this research study to the above-named individual, and I have relayed the potential benefits and possible risks of study participation. Any questions the above-named individual has about this study have been answered, and we will always be available to address any future questions

as they arise. I further certify that no research component of this protocol was begun until after this consent form was signed.

_____	_____
Printed Name of Person Obtaining Consent	Role in Research Study
_____	_____
Signature of Person Obtaining Consent	Date

Appendix Q Questionnaire for quantitative study

The Female Self-Advocacy in Cancer Survivorship (FSACS) scale

Instructions:

Please read each of the following statements carefully. The following statements reflect "self-advocacy" among female cancer survivors. "Self-advocacy" refers to how a person stands up for themself. A "cancer survivor" is anyone who has ever been diagnosed with cancer.

Think about your experiences since having cancer (whether you currently have cancer or had it in the past). For each statement, circle the number that corresponds to the response that best reflects how much you agree or disagree with each statement.

Items:

1. **I use my skills to solve problems I face as a cancer survivor.**

1.....2.....3.....4.....5.....6
strongly disagree disagree somewhat disagree somewhat agree agree strongly agree

2. **I gather information before making decisions about my cancer care.**

1.....2.....3.....4.....5.....6
strongly disagree disagree somewhat disagree somewhat agree agree strongly agree

3. **I weigh my options carefully before making important decisions about my cancer care.**

1.....2.....3.....4.....5.....6
strongly disagree disagree somewhat disagree somewhat agree agree strongly agree

4. **I prepare myself to make decisions about my cancer care.**

1.....2.....3.....4.....5.....6
strongly disagree disagree somewhat disagree somewhat agree agree strongly agree

5. **When it comes to making decisions about my cancer care, I know what my priorities are.**

1.....2.....3.....4.....5.....6
strongly disagree disagree somewhat disagree somewhat agree agree strongly agree

6. **I am comfortable asking for a second opinion.**

1.....2.....3.....4.....5.....6
strongly disagree disagree somewhat disagree somewhat agree agree strongly agree

7. I know where to get an answer if my provider can't give me one.

1.....2.....3.....4.....5.....6
strongly disagree disagree somewhat disagree somewhat agree agree strongly agree

8. I ask questions when I don't understand what my provider is telling me.

1.....2.....3.....4.....5.....6
strongly disagree disagree somewhat disagree somewhat agree agree strongly agree

9. I question my provider if I don't agree with his or her recommendations.

1.....2.....3.....4.....5.....6
strongly disagree disagree somewhat disagree somewhat agree agree strongly agree

10. I don't talk about a health concern with my provider unless I think there is a solution.

1.....2.....3.....4.....5.....6
strongly disagree disagree somewhat disagree somewhat agree agree strongly agree

11. I rarely tell my provider about the problems I am having.

1.....2.....3.....4.....5.....6
strongly disagree disagree somewhat disagree somewhat agree agree strongly agree

12. I have a hard time voicing my preferences to my provider.

1.....2.....3.....4.....5.....6
strongly disagree disagree somewhat disagree somewhat agree agree strongly agree

13. I ask my provider to explain his or her recommendations.

1.....2.....3.....4.....5.....6
strongly disagree disagree somewhat disagree somewhat agree agree strongly agree

14. I seek out support from other cancer survivors.

1.....2.....3.....4.....5.....6
strongly disagree disagree somewhat disagree somewhat agree agree strongly agree

15. Helping other cancer survivors also helps me.

1.....2.....3.....4.....5.....6
strongly disagree disagree somewhat disagree somewhat agree agree strongly agree

16. When I hear someone has cancer, I try to reach out to them.

1.....2.....3.....4.....5.....6
strongly disagree disagree somewhat disagree somewhat agree agree strongly agree

17. It helps me to know that other cancer survivors have gone through what I am going through.

1.....2.....3.....4.....5.....6
strongly disagree disagree somewhat disagree somewhat agree agree strongly agree

18. Telling other people my story makes me feel good.

1.....2.....3.....4.....5.....6
strongly disagree disagree somewhat disagree somewhat agree agree strongly agree

19. I try to raise awareness about cancer.

1.....2.....3.....4.....5.....6
strongly disagree disagree somewhat disagree somewhat agree agree strongly agree

20. I am comfortable sharing my cancer experience with others.

1.....2.....3.....4.....5.....6
strongly disagree disagree somewhat disagree somewhat agree agree strongly agree

Brief Opioid Stigma scale

Instructions:

For each statement, circle the number that corresponds to the response that best reflects how much you agree or disagree with each statement.

1. **Most people believe that a person who is addicted to opioids cannot be trusted.**

1.....2.....3.....4.....5
strongly disagree somewhat disagree unsure somewhat agree strongly agree

2. **Most people believe that a man who is addicted to opioids is dangerous.**

1.....2.....3.....4.....5
strongly disagree somewhat disagree unsure somewhat agree strongly agree

3. **Most people think that a person who is addicted to opioids is to blame for his or her problems.**

1.....2.....3.....4.....5
strongly disagree somewhat disagree unsure somewhat agree strongly agree

4. **Most people believe that a person who is addicted to opioids is lazy.**

1.....2.....3.....4.....5
strongly disagree somewhat disagree unsure somewhat agree strongly agree

5. **I believe that a person who is addicted to opioids cannot be trusted.**

1.....2.....3.....4.....5
strongly disagree somewhat disagree unsure somewhat agree strongly agree

6. **I believe that a man who is addicted to opioids is dangerous.**

1.....2.....3.....4.....5
strongly disagree somewhat disagree unsure somewhat agree strongly agree

7. **I think that a person who is addicted to opioids is to blame for his or her problems.**

1.....2.....3.....4.....5
strongly disagree somewhat disagree unsure somewhat agree strongly agree

8. **I believe that a person who is addicted to opioids is lazy.**

1.....2.....3.....4.....5
strongly disagree somewhat disagree unsure somewhat agree strongly agree

Patient-Centered Communication – Six-Item Instrument

These questions ask about your experiences with doctors and other health professionals such as nurses and physician assistants. This is not a test, and there are no right or wrong answers. Please be sure to read all answer choices before marking your answer.

1. **How much do your doctors and other health professionals make you feel comfortable asking questions?**

1	2	3	4	5
not at all	not very much	somewhat	a lot	a great deal

2. **How often do your doctors and other health professionals have open and honest communication with you?**

1	2	3	4	5
never	rarely	sometimes	often	always

3. **Many decisions need to be made in cancer care, such as decisions about treatment choices, where to go for care, or how to manage side effects. Please think about all of the decisions there have been in your care. How much do your doctors and other health professionals give you information and resources to help you make decisions?**

1	2	3	4	5	6
not at all	not very much	somewhat	a lot	a great deal	not applicable

4. **How well do your doctors and other health professionals talk with you about how to cope with any fears, stress, and other feelings?**

1	2	3	4	5	6
poorly	not very well	fairly well	very well	outstanding	not applicable

5. **How often do your doctors and other health professionals make sure you understand the steps in your care?**

1	2	3	4	5
never	rarely	sometimes	often	always

6. **Cancer patients often face uncertainties about their cancer. For example, patients may not know what will happen, how treatment is working, and how to make sense of different information and opinions. How well do your doctors and other health professionals help you deal with the uncertainties about your cancer?**

1	2	3	4	5	6
poorly	not very well	fairly well	very well	outstanding	not applicable

PROMIS® Scale v2.0 – Pain Intensity 3a

1. **In the past 7 days, how intense was your pain at its worst?**

1	2	3	4	5
had no pain	mild	moderate	severe	very severe

2. **In the past 7 days, how intense was your average pain?**

1	2	3	4	5
had no pain	mild	moderate	severe	very severe

3. **What is your level of pain right now?**

1	2	3	4	5
no pain	mild	moderate	severe	very severe

This is the end of the questionnaire. Thank you for your time and participation!

Bibliography

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