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Impact of an APRN Directed Workflow Change on Outpatient Palliative Care Referral Acceptance Rates

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Acceptance Rates

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Dedication

This DNP project is dedicated to my family who has instilled the values of education, curiosity, and empathy within me. This project is also dedicated to my husband, Myles, who has tirelessly supported me throughout this DNP program. I am so appreciative of your patience, encouragement, and cooking skills. Special thanks to Carl, who is always by my side.

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Abstract

Patients diagnosed with an advanced disease or serious illness often experience a variety of distressing symptoms that can negatively impact their functional status and quality of life. Outpatient palliative care is a medical specialty that often requires a referral from a primary care or specialty care provider who has identified a need for specialized pain and symptom management, psychosocial or caregiver distress, end-of-life care management, or goals of care discussions. Despite notable effectiveness in the provision of palliative care for patients with advanced disease and serious illness, barriers exist that prevent patients from accepting palliative care referrals even after a need has been identified by their referring provider. This DNP project aimed to increase the rate of palliative care referral acceptance rates in adult patients referred to the outpatient palliative care team within Sansum Clinic, by incorporating an APRN-led workflow change into the initial outreach process for patients referred to the team. Referral and demographic data were analyzed for this DNP project. Considerations for future educational, clinical and research opportunities are discussed.

Keywords: palliative care, outpatient, referrals, symptom burden, education, communication

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CHAPTER 1

Introduction and Background

Palliative care is patient and family-centered care that can be provided throughout the continuum of illness or disease, together with life-prolonging treatment, with the goal of alleviating disease-related symptoms, improving quality of life and relieving suffering (Conduit et al., 2020; Hagan et al., 2018; Hay et al., 2022). Integrating palliative care into the care of patients with advanced diseases and cancer has been shown to reduce symptom burden, improve patient outcomes, caregiver distress, mood and overall satisfaction with treatment outcomes, decrease utilization of aggressive medical care, reduce healthcare costs at end of life, and may improve survival (Binder et al., 2021; Conduit et al., 2020; Dillon et al., 2021; Duggan et al., 2019; Graul et al., 2020; Maciasz et al., 2013; Paiva et al., 2020; Parajuli et al., 2019; Scibetta et al., 2016; Shah et al, 2022). There are several domains of palliative care including physical, psychological, emotional, social, spiritual, existential, ethical and cultural aspects of care, as well as care for the patient at end of life (Hagan et al., 2018).

Despite improvements in cancer therapies and diagnostics, symptoms are a significant source of distress and suffering in patients with cancer (Shamich et al., 2017). Distressing symptoms may include pain, nausea, vomiting, fatigue, loss of appetite, weight loss, altered sleep, urinary or bowel elimination changes, neurocognitive, circulatory, or musculoskeletal symptoms (Parajuli et al., 2019). When patients experience severe symptom burden and have been diagnosed with progressive advanced disease, they are often referred to palliative care by their primary care provider, oncologist, or specialty provider. Referrals are often placed to assist in the management of uncontrolled pain or symptoms, to

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assist in providing psychosocial support, complex medical decision making, goals of care discussion and advance care planning. Despite the need for palliative care for the management of pain, symptoms and aspects of care, referrals to palliative care are often not accepted by patients who could benefit from palliative care resources. Without proper symptom management, goals of care discussions and psychosocial support, many patients and their caregivers struggle to find comfort physically, emotionally, and spiritually in the advanced stages of their disease. This project aims to identify barriers and facilitators to palliative care referral acceptance and how changes in patient outreach may improve referral acceptance rates.

Skillful communication is one of the pillars of palliative care and is fundamental to palliative care referral acceptance. Palliative care communication skills include being calm and open minded, displaying appropriate emotions, asking for permission, and assessing a patient's readiness and comprehension prior to initiating a challenging topic (Bennardi et al., 2020; Kirby et al., 2014; Saretta et al., 2022). Professionally trained nurses are uniquely skilled to care for and communicate with patients at all stages of life and disease states. Palliative care trained registered nurses are also skilled in care coordination, patient and caregiver education, symptom management and assessment. The Edmonton Symptom Assessment Scale – revised (ESAS-r) is a validated and widely used symptom assessment tool within palliative care and oncology and has been chosen for symptom assessment for this QI (quality improvement) project (Nekolaichuk et al., 2019) (see Appendix A). As part of an initial outreach telephone call, utilization of the ESAS-r provided by a palliative care registered nurse can assist in identifying pain and symptom burden and can assess and measure the intensity and severity of symptoms for patients newly referred to palliative care.

It is hoped that with a palliative care trained registered nurse on the forefront of discussions with referred patients in need, that patients and their caregivers may be more willing to accept referrals to palliative care.

<center>**Significance**</center>

Despite appropriate referrals to palliative care, it is estimated that about 60% of patients who may benefit from palliative care do not receive it (Dillon et al., 2021). Patients are often not receiving the benefits of palliative care due to several barriers which prevent patients from accepting palliative care consultation. Patient, family and caregiver-related barriers to palliative care referral acceptance include lack of knowledge or awareness of palliative care, misconceptions or fears related to palliative care, as well as cultural, religious, and generational barriers (Burdette et al., 2005; Cai et al., 2022; Dosani et al., 2020; Flieger et al, 2020; Kirby et al., 2014; Maciasz et al., 2013; McVeigh et al., 2019; Paiva et al., 2020; Parajuli et al., 2020; Saretta et al., 2022; Steiner et al., 2020; Zimmermann et al., 2016). Underutilization of palliative care may lead to unrelieved pain and symptoms, decreased quality of life, patient and caregiver distress, increased health care spending and more aggressive care at end-of-life. Earlier identification of unrelieved pain, symptoms, and psychosocial distress can lead to earlier palliative care and proper management, ultimately improving quality of life for patients and caregivers (Binder et al., 2021; Dillon et al., 2021; Dosani et al., 2020; Hoerger et al., 2017; Meier & McCormick, 2022; Scibetta et al., 2016; Zimmermann et al., 2016).

<center>**Clinical Question/PICOT**</center>

The clinical question guiding this QI project is in adult patients with serious illness and advanced disease referred to the outpatient palliative care team (P), how does a change

in the current outpatient palliative care workflow process incorporating palliative care board-certified registered nurses (I) compared with current practice (C), affect referral acceptance rates to palliative care (O) within an 8-week period (T)?

Additional clinical questions pertaining to this QI project also include:

1. Do referred patients with a higher symptom burden (as determined via ESAS-r scores) choose to accept palliative care referrals over referred patients with lower symptom burden?

2. Does a higher symptom burden (as determined via ESAS-r scores) impact the acceptance rate of palliative care referrals?

3. Do patients with a higher symptom burden require longer discussion with palliative care RN during outreach telephone call?

Goals of Project

The goal of this evidence-based practice (EBP) QI project is to evaluate the impact of an advance practice registered nurse (APRN) directed workflow change on outpatient palliative care referral acceptance rates. As palliative care is such a valuable resource to patients, families and caregivers suffering from advanced and progressive illnesses, improving acceptance rates to palliative care will help to close this gap in patient care. The purpose of this QI project is to increase outpatient palliative care acceptance rates for patients with serious and progressive illnesses who are referred to palliative care.

Conceptual Model

The Donabedian framework (Donabedian, 1988) was applied to this QI project to organize, categorize and evaluate the impact of a workflow change on palliative care referral

acceptance rates. The quality of health care under Donabedian's framework can be classified under the three categories: structure, process, and outcomes (Donabedian, 1988). The structure refers to the outpatient palliative care setting, adult patients referred to palliative care, the palliative care team, qualifications of the palliative care registered nurses and providers, and the organizational resources. The process refers to the new workflow change that will take place within the outpatient palliative care clinic and includes providing and receiving care which will include skilled palliative care communication and patient education provided by palliative care trained registered nurses. The outcome signifies the impact of the care received, which may lead to increased rates of palliative care referral acceptance, improved palliative care utilization and hopefully improved patient outcomes and quality of life.

Summary

The goal of this QI project was to improve palliative care referral acceptance rates by patients referred to outpatient palliative care. Palliative care aims to provide an extra layer of support for patients and families suffering from advanced disease and serious illness. With greater acceptance rates to palliative care, a greater number of patients and families may benefit from pain and symptom management, psychosocial support, improved quality of life and less aggressive end-of-life care.

CHAPTER 2

Review of the Literature

Patients diagnosed with a serious illness often experience a variety of distressing symptoms that affect their quality of life and functional status as their disease progresses. Interdisciplinary palliative care teams provide specialized medical care that focus on pain and symptom management, psychosocial, emotional and spiritual support for patients and families, and guidance with advance care planning and goals of care discussions (Hagan et al., 2018; Meier & McCormick, 2022). Patients who receive palliative care have reported improved quality of life, pain and symptom management, understanding of illness and prognosis, end-of-life preparation and experiences, and smoother transitions to hospice when the time is right (Dillon et al., 2021). Despite notable effectiveness in palliative care for patients with advanced disease and serious illness, barriers exist that prevent patients from accepting palliative care referrals once made by their primary or specialty provider. The purpose of this literature review is to examine identified barriers and facilitators and best practice interventions to improve access to palliative care.

Definitions of Terms and Concepts

Palliative Care is defined by the World Health Organization (WHO) as: "An approach that improves the quality of life of patients and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual" (WHO, 2020, para. 1). Palliative care is care provided by a specialized interdisciplinary team of palliative care-trained professionals who

work together with a patient's medical team to support and provide relief of symptoms and stress of the illness (Center to Advance Palliative Care [CAPC], n.d., para. 1).

For this literature review, outpatient palliative care is defined as care for "[patients] who are neither hospitalized nor on hospice care who need access to palliative care in a community clinic or office setting such as a cancer center" (CAPC, 2020, para. 1). The term supportive care is also used throughout the literature and is synonymous with palliative care.

A registered nurse (RN) is defined as an "individual who has graduated from a state-approved school of nursing, passed the NCLEX-RN Examination and is licensed by the state board of nursing to provide patient care" (NCSBN, n.d.). RNs "form the backbone of health care provision in the United States" (American Nurses Association [ANA], n.d., para. 7). Responsibilities of an RN include performing physical exams and health histories, critical decision making, health promotion, educating and counseling patients, administering medications, coordinating care, and collaborating with various health care providers (ANA, n.d.). The RN specialty area of practice for purposes of this project is palliative care.

An advanced practice registered nurse (APRN) is considered an umbrella term used by some nursing associations and states to collectively include nurse practitioners, nurse midwives, and nurse anesthetists (Buppert, 2021). For this literature review the APRN is a nurse practitioner (NP). An NP is a health care provider who has completed a masters or doctoral degree program, with advanced clinical training beyond their initial RN preparation and includes national certification, peer review, and practice under rules and regulation in the state in which they practice (American Association of Nurse Practitioners [AANP], n.d.). NPs work independently and collaboratively with health care professionals and

provide a full range of primary, acute and specialty health care services (AANP, n.d.) The

nurse practitioner specialty area of practice for this project is palliative care.

A palliative care referral is a medical order placed by a health care provider who

may be a physician, nurse practitioner, or physician assistant. The referral is placed

electronically through the electronic medical record in a patient's chart or via fax if sent by

an outside health care organization or hospital. Common reasons for palliative care referral

include pain and symptom management, psychosocial distress, end-of-life care

management, caregiver distress, advance care planning or goals of care discussion for

patients with advanced illness.

Symptom burden is defined as "the subjective, quantifiable prevalence, frequency,

and severity of symptoms placing a physiologic burden on patients and producing multiple

negative, physical, and emotional patient responses" (Gapstur, 2007, p. 673).

Literature Review

The literature search was performed from February 2022 to March 2022 and again

from September 2022 to November 2022. Literature for inclusion was located within

CINAHL, Cochrane, and PubMed databases. Primary search terms included: *palliative care,*

supportive care, utilization, outpatient, education, acceptance, perceptions, referrals,

barriers, enablers, facilitators, education, symptoms, symptom burden, appointments,

consultation and *communication* in various combinations and orders via Boolean

connectors. Inclusion criteria included English-language studies, articles published between

2015-2022, studies including adult patients, 18 years or older, and involving outpatient or

ambulatory care settings. Exclusion criteria included study protocols, studies involving

home care, hospice, or rehabilitation settings. A review of the literature and information

from Center to Advance Palliative Care (CAPC), Centers for Disease Control and Prevention (CDC), and National Comprehensive Cancer Network (NCCN) were reviewed and utilized for this project.

Symptom Burden in Palliative Care

Patients with advanced cancer and serious illness often face a multitude of distressing symptoms that may include one or many of the following: pain, shortness of breath, fatigue, insomnia, nausea, vomiting, constipation, diarrhea, depression, anxiety, worry, existential distress, decreased appetite, dry mouth, sadness, grief, and frustration (Hui & Bruera, 2017; Kirby et al., 2014). These symptoms can greatly affect quality of life and the ability to complete activities of daily living independently. Palliative care aims to reduce symptom burden and alleviate worry, distress, depression, and anxiety. Specialty palliative care has been shown to improve mood and psychological symptoms in various studies (Ernecoff et al., 2020; Kluger et al., 2020; Reiser et al., 2019). Studies by Bekelman et al. (2018) and Reiser et al. (2019) showed statistically significant decreases in anxiety after interdisciplinary palliative care team interventions were implemented within heart failure and metastatic breast cancer populations over three-month intervention periods, respectively.

In a study by Bock and colleagues (2022), patients with Parkinson's disease and related disorders who received outpatient integrated palliative care showed significant improvements in self-perception, drowsiness, constipation, confusion, and apathy at six months and significant improvement in nausea, tiredness, drowsiness, shortness of breath, constipation, apathy, and well-being at 12 months. Shah and colleagues (2022) conducted a retrospective data review of cancer patients who attended an outpatient palliative care clinic,

with results demonstrating significant improvements in sleep, pain, wellbeing and overall

symptom composite scores between initial appointment and median follow up time of four

weeks between clinic appointments. About 30% of patients had an opioid or adjuvant pain

medication initiated or titrated upon initial visit to palliative care along with other

medication changes made for nausea, bowel issues, insomnia, and mood (Shah et al., 2022).

In patients with advanced cancer, outpatient palliative care has also shown to significantly

improve pain, fatigue, nausea, depression, anxiety, drowsiness, appetite, well-being,

dyspnea, and sleep for patients who presented with moderate to severe symptom intensity

(Shamich et al., 2017). These findings demonstrate the need for timely and effective

symptom management in the outpatient palliative care setting for patients with progressive

and serious illness and the efficacy of palliative care in improving clinically significant

symptoms.

Palliative Care Referrals

Palliative care is a medical specialty that often requires a referral order placed by a

health care provider for care delivery to be initiated and can be provided concurrently with

curative or disease-modifying treatment. Early palliative care is defined as meeting for

initial consultation with a palliative care provider more than 90 days before death versus late

palliative care occurring within the last 90 days of life (Binder et al., 2021; Scibetta et al.,

2016). The literature demonstrates when patients and caregivers receive palliative care

earlier in the course of their illness, they have reduced symptom burden, improved quality of

life, feel better equipped to cope with their illness, and have greater levels of comfort

(Binder et al., 2021; Dillon et al., 2021; Dosani et al., 2020; Hoerger et al., 2017; Meier &

McCormick, 2022; Zimmermann et al., 2016). Early palliative care referrals have been

associated with lower hospital costs, overall healthcare spending, and lower rates of visits to the emergency department, hospital admissions, and transfers to the intensive care unit (ICU) in the last 30 days of life (Scibetta et al., 2016). The literature highlighted several barriers and facilitators to the delivery of palliative care and referrals made to palliative care by providers (Bennardi et al., 2020; Cai et al., 2022; Conduit et al., 2019; Dillon et al., 2021; Flieger et al., 2020; Maciasz et al., 2013; Paiva et al., 2020). Referrals to palliative care are made at varying times during a patient's illness trajectory, including early in disease, without active cancer treatment, problem-based, and late disease state (Dillon et al., 2021). Predictors of palliative care referrals include older age, cancer diagnosis, and poorer performance status (Conduit et al., 2021; Graul et al., 2020; Thoonsen et al., 2019). Patients are more likely to require supportive care as they age, become frailer, and develop more complex and comorbid illnesses. Patients with advanced cancers may have disease-related or treatment-related symptoms that require proper management and have greater need for goals of care and end of life discussions that can be addressed by palliative care teams.

Graul et al. (2020) references National Comprehensive Cancer Network (NCCN) and notes the extensive study of strategies to increase palliative care communication among health care providers and barriers to specialty palliative care referral within medical oncology departments. The NCCN provides resources and guidelines to assist in improving and providing quality oncology care to patients (NCCN, 2022). The NCCN advise oncologists to follow NCCN Palliative Care guidelines which have established criteria for consultation and referral to palliative care (NCCN, 2022). Criteria for palliative care referral includes patient characteristics such as advanced disease, multiple and/or severe comorbid conditions, rapidly progressive functional decline or poor performance status, need for goals

of care clarification, resistance to engage in advance care planning, poor pain management, high symptom burden, high level of psychological distress, frequent emergency room visits or hospitalizations, ICU-level care, communication barriers, request for hastened death, complex patient, family or caregiver circumstances, and oncology care team or staff challenges (NCCN, 2022). These guidelines can be useful to primary care and other specialty providers to determine criteria for patients appropriate for palliative care referral.

Barriers to Palliative Care Referral Acceptance

Palliative care is often an underutilized resource due to patient, family, and caregiver related barriers; providers' beliefs and experiences also vary and influence referral patterns to palliative care (Dillon et al., 2020). Factors that may influence health care providers referrals to palliative care may include overestimation of patients' prognosis, uncertainty due to a new therapeutic regimen, lack of time, may prefer to self-manage, limited ability of palliative care resources in their community or workplace, and the worry that discussions surrounding advance care planning or palliative care may distress the patient (Conduit et al., 2019). Once a health care provider places a referral order for a patient to seek palliative care, there are several barriers to palliative care referral acceptance by patients, caregivers, and family members. Identifying barriers to palliative care referral acceptance will help to improve the current workflow within outpatient palliative care once a referral is received. This literature review revealed the following themes related to barriers to palliative care referral acceptance and include patient and caregiver misconceptions or fears, communication barriers in palliative care, and cultural, religious, and generational barriers.

Patient and Caregiver Misconceptions or fears

When palliative care is initially introduced, patients often experience shock and fear and associate palliative care with death, dying, hopelessness, and dependency (Dosani et al., 2020; Paiva et al., 2020; Zimmermann et al., 2016). Many patients believe that palliative care is synonymous with hospice care, comfort care, or end-of-life care, which may lead to a reluctance in accepting referral to palliative care (Flieger et al., 2020; Steiner et al., 2020; Zimmermann et al., 2016). Once referred, patients fear that their doctor is giving up on them, that no further treatment is available, or that patients must stop treatments to receive palliative care (Dosani, et al., 2020; Flieger et al., 2020; Steiner et al., 2020). There are a variety of sources from which perceptions surrounding palliative care may originate. Many patients learn about palliative care through interactions with their health care provider, their oncologist, during a health care system experience caring for a friend or family member, their own medical care, or from the media or films (Zimmermann et al., 2016). Despite advanced medical training, providers and oncologists still view palliative care as end-of-life care (Maciasz et al., 2013).

Influenced by patient misconceptions, many providers report apprehension towards referring patients to palliative care for fear of leading the patient to believe they are giving up on them or losing hope (Flieger et al., 2020). Lack of knowledge or clear understanding by patients and caregivers of what palliative care is, may lead to decreased perceived need for palliative care, underutilization of palliative care, increased pain and symptom burden, and psychosocial distress (Hoerger et al., 2017; Maciasz et al., 2013). A perceived lack of ability to afford palliative care services is also a barrier for palliative care referral

acceptance (McVeigh et al., 2019). Therefore, efforts to change or address these misconceptions and fears may improve palliative care referral acceptance.

Communication Barriers and Terminology in Palliative Care

Language and semantics are important when educating patients about palliative care as many patients and caregivers know little about the care. Many health professionals prefer to avoid discussions regarding goals of care, patient and caregiver emotions, and prognosis as it may destroy hope or cause harm to their patients (Paiva et al., 2020; Saretta et al., 2022). Because of this avoidance, health care providers often make referrals to palliative care, with hopes that palliative care teams will assist with difficult and emotional discussions. However, when referring patients to palliative care, the transition from their usual health care to additional supportive or palliative care is often poorly communicated from provider to patient (Kirby et al., 2014). The term "palliative care" may be seen as distressing due to misconceptions by patients, families, and health care providers, and may pose a barrier to referral acceptance. In a randomized telephone survey of patients with advanced cancer, the term "supportive care" was associated with higher future perceived need, better understanding, and was viewed more favorably than the term "palliative care" (Maciasz et al., 2013). Patients were more likely to view palliative care as end-of-life care and supportive care as a service that provides support for psychological, mental and social needs, as well as medical information and communication. Oncologists and referring providers may choose to substitute the term palliative care with supportive care to decrease barriers to service use and acceptance (Maciasz et al., 2013). Therefore, having communication with a knowledgeable palliative care provider may improve communication barriers and improve referral acceptance.

Cultural, Religious, and Generational Barriers to Palliative Care Referral Acceptance

Palliative care patients have diverse cultural, religious, and generational preferences. Within healthcare, generational stereotypes exist among healthcare providers along with cultural views of aging. Some health care providers only refer patients to palliative care when they are near death or suffering from a terminal illness, often preventing older people from receiving necessary palliative care when needed (Saretta et al., 2022). Parajuli and colleagues (2020) performed a systematic literature review of 19 studies that identified barriers to hospice and palliative care utilization in older adults. The authors' review of the literature revealed that older adults, males, racial minorities, unmarried individuals, those with low socioeconomic status, or those living in rural areas were less likely to utilize palliative or hospice care (Parjuli et al., 2020). The outcomes from Parajuli and colleagues' study (2020) may assist palliative care teams in identifying higher risk populations of patients who may be underutilizing palliative care.

Living in a rural area or geographically distant from local palliative care service providers may also pose a barrier to palliative care referral acceptance (Cai et al., 2022; McVeigh et al., 2019; Parajuli et al., 2020). Cai et al. (2022) performed a literature review of 28 studies that assessed palliative care access barriers and/or facilitators from the patient and provider perspective within rural areas. Barriers identified included inadequate knowledge and awareness of palliative care existing among patients and providers, poorly structured palliative care systems available, communication challenges, poor health literacy and language barriers, as well as diverse cultural practices amongst patients and caregivers (Cai et al., 2022). For patients living far from local palliative care services or living in rural areas, McVeigh et al. (2019) report that telemedicine can be a beneficial platform to provide

care to patients that would otherwise have difficulty accessing care. The authors also reveal that war veterans, refusing to accept palliative care referral, may view palliative care as "surrendering" to their illness (McVeigh et al., 2019).

Faith-based beliefs and patients' view of death may impact acceptance of palliative care. Patients with more conservative religious beliefs may view that end-of-life decision making falls under the religious authority, and those with more liberal beliefs assert their autonomy, or right to decide between life and death (Burdette et al., 2005; Dosani et al., 2020). For many South Asian populations and minority groups, the role of the family providing care to patients at the end-of-life is paramount and therefore may not accept a palliative care referral (Dosani et al, 2020). Therefore, palliative care teams must work to identify cultural, religious, and generational barriers and those who are at-risk for underutilizing palliative care. Once identified, palliative care providers can use culturally and generationally sensitive language to improve patient and caregiver knowledge and hopefully improve referral acceptance to palliative care.

Facilitators to Palliative Care Referral Acceptance

Knowledge/Education for Patients and Caregivers

Due to several misconceptions and fears regarding palliative care, it is important to place an emphasis on proper education and increasing awareness of palliative care to improve palliative care utilization. Many patients, with advanced cancer, do not understand that their disease is incurable despite treatment with chemotherapy which suggests that communication between providers and their patients is lacking (Scibetta et al., 2016). Steiner and colleagues (2020) interviewed adults with congenital heart disease with results indicating most participants experienced negative emotional impacts of their disease, were

uncertain about their future, and wanted to know as much as about their prognosis, disease progression and condition as possible.

In a systematic review of palliative care utilization literature by Bennardi and colleagues (2020), several studies showed that patients and families had a lack of knowledge or low awareness of palliative care or were unable to define palliative care or its scope of practice. Studies also demonstrated a lack of guidelines for palliative care education and lack of education provided. Palliative care was utilized more in patients that had increased knowledge of palliative care benefits (Bennardi et al., 2020).

Heorger and colleagues (2017) provided education to cancer patients using plain-language and a graphical summary of the results of an earlier palliative care study that was performed in 2010. The earlier palliative care study examined the effects of a team-based palliative care intervention that was integrated within standard oncology care for metastatic lung cancer patients. The education provided by Hoerger and colleagues (2017) included background information on palliative care, and observed benefits for quality of life, depression and survival based on the earlier palliative care study results. The education had a positive impact on cancer patients' view of palliative care, viewing it as "less scary" (p. 538), more efficacious and showed behavioral intentions that they were more likely to utilize outpatient palliative care if referred (Hoerger et al., 2017). Providing palliative care education to patients and their families can help to decrease patient fears of abandonment of their primary or specialty providers, normalize palliative care and address negative associations (Hay et al., 2017). Therefore, putting emphasis on palliative care education during initial outreach to referred patients and caregivers will help to dispel myths and misconceptions of palliative care.

Communication as a Facilitator to Palliative Care Referral Acceptance

Skillful communication is one of the main facets of palliative care and is crucial in effective referral acceptance to palliative care. In a systematic review of the literature, Saretta and colleagues (2022) found that palliative care communication skills influence communication among health professionals and older adults. The use of simple language, being open mannered, asking adequate questions to understand a patient's comprehension and readiness, and asking for consent before initiating a challenging topic of conversation helps to facilitate conversation and decreases anxiety (Bennardi et al., 2020; Saretta et al., 2022). Building rapport, creating a relationship, and understanding when a patient is ready and wants to communicate are also facilitators to communication (Saretta et al., 2022). It is also important to personalize communication, respecting the identity of each patient who may come from a different generational, cultural, or religious background.

Professional registered nurses are educated on how to engage in sensitive conversations with a supportive, non-threatening, and calm presence and to display appropriate emotions when discussing patient and family values and when forming a nurse-patient relationship (Hagan et al., 2018; Kirby et al., 2014). With expert communication skills, palliative care nurses can facilitate difficult discussions regarding prognosis, treatment options, goals of care, advance care planning and medical decisions (Hagan et al., 2018). Hospital-based nurses were interviewed in a study by Kirby and colleagues (2014) regarding their role in managing transitions to palliative care. Nurses indicated the importance of skillful communication surrounding mortality and futility, ongoing practical needs for patients and families, and listening skills when engaging in conversations with patients who are considering referral to palliative care. Education and training specific to

communication skills and palliative care for nurses and other health care professionals is a facilitator to palliative care communication. Training courses such as End of Life Nursing Education Consortium (ELNEC) Geriatric Curriculum or CAPC courses for palliative care can help to develop communication skills and competencies (Saretta et al., 2022). Thus, changing the workflow to allow palliative care trained professional registered nurses, with exceptional communication skills, can help to improve palliative care referral acceptance.

Comprehensive Needs Assessments in Palliative Care Referrals

Symptom assessment tools and review of patient records or charts help to identify patients who are at greatest need for palliative care. Referrals to palliative care and social work supportive services increased significantly following a purposeful nurse-led assessment and chart audit of female patients with metastatic breast cancer (Reiser et al., 2019). The assessment was structured and included evaluation of the patient's electronic medical record to include tumor and treatment status, patient-reported symptoms, social service or financial needs, provider interactions, calls to the clinic, and medications. In a study by Skaczkowski et al. (2018), referrals to palliative care were more likely to be accepted by oncology patients who had a greater number of disease-related problems.

Hay and colleagues (2017) interviewed gynecologic oncologists focusing on practices, attitudes, and experiences surrounding outpatient palliative care. Due to patients' fears and the known stigmas surrounding the term palliative care, gynecologic oncologists have found that if they focus the palliative care referral on symptom management it helps patients build an earlier relationship with palliative care providers. Therefore, if palliative care nurses use symptom assessment in their initial outreach phone call and use it as a major

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focus of the intended care delivery, it may help to decrease patient fears and encourage

acceptance of referral.

Symptom Assessment Tools

Patients with advanced disease and serious illness often have symptoms that are not

well addressed, and many have several symptoms that require immediate attention and

management. Patients often experience substantial symptom burden that can begin from

diagnosis and can intensify as disease progresses. On average, patients with cancer report up

to 8-12 symptoms that affect their quality of life and function (Hui & Bruera, 2017). With

appropriate symptom assessment and management, patients may experience improved

quality of life, decreased levels of stress and suffering. There are several accepted symptom

assessment tools used to assess for and measure intensity and severity of symptoms. For

purposes of this project, the Edmonton Symptom Assessment System (ESAS-r)

(Nekolaichuk et al., 2019) was chosen for symptom assessment (see Appendix A).

Edmonton Symptom Assessment System - Revised (ESAS-r)

The ESAS-r tool has been validated, translated into over 20 languages, and is a

comprehensive assessment tool commonly used in oncology, palliative care, nephrology,

and other specialties in both the outpatient and inpatient settings (Hui & Bruera, 2017;

Nekolaichuk et al., 2019). A self-reporting tool for patients, the ESAS-r measures symptom

severity or intensity for nine or ten common symptoms of advanced cancer including pain,

tiredness, nausea, depression, anxiety, drowsiness, appetite, wellbeing, shortness of breath

(Nekolaichuk et al., 2019). The ESAS-r has been incorporated into electronic health records,

has been used as a trigger for palliative care referrals, and provides health care professionals

with an easy-to-use tool for symptom screening, evaluating for symptom clusters and

longitudinal monitoring of symptoms (Hui & Bruera, 2017; Lee et al., 2020). Used as a pre-screening tool, obtaining a baseline ESAS-r score can aid in identifying symptom burden for patients with advanced disease or cancer, who may benefit from palliative care services (Lee et al., 2020). Higher physical symptom and total symptom distress scores (SDS) resulting from completed ESAS-r assessments have been associated with decreased survival (Hui & Bruera, 2017). For purposes of this project, the ESAS-r will be used by the nurses to direct the initial conversation and capture symptoms associated with their diagnosis.

Gaps in the Literature

Identifying gaps in the literature guide evidence-based projects and further research in palliative care. The literature cited addresses barriers and facilitators to palliative care referrals and referral acceptance and demonstrates ways in which outpatient palliative care can improve symptom burden and quality of life for patients with advanced and serious illness (Bennardi et al., 2020; Cai et al., 2022; Conduit et al., 2019; Dillon et al., 2021; Dosani et al., 2020; Flieger et al., 2020; Hoerger et al., 2017; Maciasz et al., 2013; Paiva et al., 2020; Parajuli et al., 2020; Saretta et al., 2022; Steiner et al., 2020; Zimmermann et al., 2016). Choosing to forgo a palliative care consultation may result in poorer symptom control, decreased psychosocial support, more frequent trips to the emergency department or hospital and may result in more aggressive care at end of life (Scibetta et al., 2016). To date, this is the first evaluation addressing the lack of referral acceptance in palliative care by changing the outpatient palliative care clinic workflow to incorporate nurses as the primary outreach agent.

Conclusion and Implications of Evidence and Research

This literature review provides evidence on the methods by which health care teams use education to increase knowledge of palliative care to improve palliative care utilization by referred patients with serious illness. The literature also supports that with improvements in communication, and specifically, palliative care communication skills can increase palliative care utilization (Bennardi et al., 2020; Hagan et al., 2018; Kirby et al., 2014; Maciasz et al., 2013; Saretta et al., 2022). The goal of this evidence-based project is to increase referral acceptance rates to palliative care by increasing patient and caregiver knowledge of palliative care, dispelling misconceptions and fears, and providing effective communication by trained palliative care nurses.

CHAPTER 3

Methodology

This chapter will outline the methods utilized in this EBP QI project. This project aims to improve referral acceptance rates by changing the current workflow surrounding patient outreach once an outpatient palliative care referral is placed.

Design

This EBP QI project utilized the Donabedian framework to guide and evaluate this project to assess the impact of a workflow change on acceptance rates of palliative care referrals and provide insight into rejections to palliative care referrals. Donabedian's model has three distinct categories; Structure, Process and Outcomes, which will be used as inferences during this quality improvement project (Donabedian, 1988).

Structure

For purposes of this project, the structure signifies the current setting of the outpatient palliative care team within Sansum Clinic, the current workflow, and population of adult patients (18 years and older) with serious or life-limiting, progressive illness who have been referred to the palliative care team. The structure also includes organizational structure such as medical staff organization of the outpatient palliative care team (one coordinator, one medical assistant, three palliative care trained registered nurses (RN); two part-time RNs, one full-time RN, one social worker, one palliative care nurse practitioner, and one palliative care physician director) and methods of reimbursement (palliative care specialty care paid for via private insurance, Medicare, or Medicaid).

The current workflow structure includes initial patient outreach by the palliative care coordinator; the coordinator does not have any nursing or palliative care training, with most

of her exposure to palliative care occurring with on-the-job training. Referral orders are placed by referring providers via the electronic medical record (EMR); once a referral is placed electronically, the referral order is displayed on the palliative care coordinator's referral list within the coordinator's login via the EMR. The coordinator then reviews the patient's medical chart within the EMR for appropriateness of the referral. If uncertain that the referral is appropriate, the palliative care trained nurses are often asked for assistance with chart review. If the referral is deemed inappropriate for outpatient palliative care (i.e., in the setting that the patient requires in home supportive care services, hospice care or the patient is more appropriate for chronic pain management specialists), the coordinator or nursing staff notifies the referring provider that a more appropriate referral should be placed.

Once deemed appropriate for outpatient palliative care services, the coordinator calls and speaks to the referred patient or patient's caregiver, without a formal script, with the goal of setting up an initial consultation visit with either the palliative care physician director or nurse practitioner. If the patient or caregiver agrees to an initial visit, the coordinator schedules the patient for consultation. The coordinator briefly documents any important notes from the telephone call within the patient chart in the EMR which may include patient or caregiver questions, concerns, or symptoms to be addressed by the palliative care providers or nursing staff. If the patient or caregiver declines to meet with palliative care for an initial visit, the coordinator documents the referral denial and brief description of the outreach telephone call within the patient's chart in the EMR. At present, the length of the initial outreach telephone call is not measured, tracked, or documented.

Setting

The EBP project site is a community-based palliative care program titled the

"Palliative Care and Advance Care Planning" (PC-ACP) program. The PC-ACP is one of

several multidisciplinary teams within a non-profit outpatient health care system on the

California Central Coast and was established in the fall of 2019. The PC-ACP program cares

for patients with serious and life-limiting illness with distressing symptoms, patients and

families struggling with complex medical decision making or whose goals of care appear to

be in conflict, and patients in need of care coordination throughout the course of a complex

illness. Care is provided in a community, outpatient setting. The PC-ACP program clinic

offices are embedded within the outpatient health care system's cancer center. Patients are

seen for in-person visits within the clinic and via video telemedicine if they are unable to

travel to the clinic due to financial or transportation issues, geographic distance or if the

patient is too symptomatic to travel. The PC-ACP program is new for the health system and

on average the team cares for a census of 350 patients, with an estimated 360 referrals each

year. The PC-ACP program covers the five-county area of Santa Barbara, Ventura, Kern,

Tulare, and San Luis Obispo counties.

Population/Sample

The EBP project population included patients referred to the PC-ACP program. Three

RNs who are board certified in palliative care currently work on the team. The principal

investigator (PI) is a palliative care board certified advanced practice registered nurse

(APRN) who is licensed as an adult gerontology acute care nurse practitioner. The PI works

both independently and collaboratively with the palliative care physician director as a

palliative care provider on the PC-ACP team. The patients referred to the PC-ACP program

were identified immediately when the referral was submitted via the EMR. Primary inclusion criteria for the patients included adult patients 18 years or older with acute and/or chronic and progressive advanced disease process or pain related to their illness who live within the five surrounding counties (with ability to attend outpatient clinic visits or access video telemedicine if home-bound or are challenged geographically from attending in-person visits regularly). Exclusion criteria included referred patients who have chronic pain, pediatric patients, or if patient is mistakenly referred to palliative care instead of hospice or home care. There was no patient recruitment involved in this project; patient-related data was obtained from EMRs of those patients who have been referred to palliative care by a referring provider.

Process

The second component of Donabedian's (1988) framework is the process, which indicates what is done to give and receive care. The current process includes providers identifying a need and placing a referral order to outpatient palliative care, and the palliative care coordinator reaching out to patients or their caregivers to schedule an initial consultation. After discussion with the palliative care physician director, the PI determined that a workflow change incorporating palliative care trained nurses into the initial patient outreach process could improve palliative care referral acceptance. With the new process, the palliative care trained RN responsibilities included reviewing referred patients' charts for appropriateness of consult; if deemed appropriate the RN made the initial outreach telephone call to the patient and/or caregiver rather than the coordinator. During the outreach telephone call the RN assessed the patient's understanding of palliative care, provided education regarding palliative care benefits and resources, determined willingness

to make appointment for initial consult, answered questions, addressed concerns, and completed a symptom assessment using the Edmonton Symptom Assessment System - Revised (ESAS-r).

Several meetings to discuss the EBP and gather input with the coordinator, palliative care trained RNs, and palliative care physician director occurred prior to the start of the quality improvement project. The meetings addressed the change in workflow for the coordinator and RNs, with some noted concerns from the RNs that the outreach telephone calls to newly referred patients might add to their busy workload. It was determined that the three RNs share the workload as they do currently with triaging patient related issues, symptoms, concerns, and refill requests and that the added outreach telephone calls would not be too time consuming. During these discussions the coordinator stated that she never received formal nursing, palliative care or communication skills training. The coordinator also shared that many conversations have been challenging when making initial outreach telephone calls, as patients and caregivers become upset with her stating, "You called me too soon", "I'm not dying", or asking, "What is palliative care?", unaware that a palliative care consult was placed by the referring provider (M. Rodriguez, personal communication, September 12, 2022). This feedback supports the literature that many misconceptions, fears, lack of palliative care education and awareness are present within our patient population.

Prior to the start of the workflow change, the RNs asked the Sansum Clinic Information Technology (IT) team to create a smart phrase within the Epic/Wave EMR to assist with electronically documenting their telephone calls. This is separate from the EBP documentation and would have helped with streamlining the electronic documentation process. Unfortunately, the nurses did not receive a smart phrase as requested; following

each call they typed a summary of their call into the EMR. The current RN workflow requires documentation in the patient's chart within the EMR for every telephone call or encounter made between RN and patient or caregiver. The smart phrase would have included purpose of outreach telephone call (palliative care referral) and if patient agreed to the referral (if yes, call will be transferred to the coordinator; if no, with space to enter comment for reason why the referral was denied; if not sure, patient agrees or disagrees to a follow up in a week with space to enter comments).

The duration of this quality improvement project participation took place over 9 weeks. Week one included RN education/intervention with PI to review new workflow, script/communication guide, ESAS-r tool and how to document necessary data. The workflow change took place during weeks 2-9 (eight weeks total) during normal work hours, Monday through Friday.

Instrument

The PI created a script for the palliative care trained RNs to use during their initial outreach telephone call to patients referred to palliative care as a communication guide and a method of standardization for each call (see Appendix B). The script incorporated the barriers and facilitators to palliative care referral acceptance that were noted within the literature review including dispelling misconceptions and fears of palliative care, providing palliative care education and benefits and uses clear and effective communication. The script also incorporated the ESAS-r tool (Nekolaichuk et al., 2019) (see Appendix A). The ESAS-r was provided to the palliative care trained RNs to utilize as part of their communication guide/script (see Appendix B). The ESAS-r is free and available to use in the public domain and does not require formal approval; this was confirmed via email

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correspondence with Viki Muller, research/project coordinator for Covenant Health within Alberta Health Services (see Appendix C). The PI completed a permission form on the Alberta Health Services website as requested by the ESAS-r developers for their data tracking purposes only (Alberta Health Services, 2022).

The validated ESAS-r tool is used in clinical practice to measure and assess the severity and intensity of nine or ten common symptoms of advanced cancer and patients receiving palliative care (Nekolaichuk et al., 2019). Symptoms are scored by patients using an 11-point numeric rating scale ranging from zero to 10; zero if no symptom is present, 1-3 if symptoms are mild, 4-6 if symptoms are moderate, and 7-10 if symptoms are severe (Hui & Bruera, 2017). Individual symptom scores are tracked as well as the symptom distress score (SDS) which is the total value of all emotional, physical and well-being symptoms listed on the ESAS-r instrument. The ESAS-r was used in several studies within the literature to measure symptom burden in patients with serious illness or advanced disease (Hui & Bruera, 2017; Hui et al., 2020; Kluger et al., 2020; Lee et al., 2020; Schenker et al., 2021; Wong et al., 2019). Following each telephone call, the script/nursing evaluation sheet was collected, and the PI manually entered data from each telephone call, including patient demographics, ESAS-r scores, RN comments and PI interpretations onto a PI Data Collection Sheet (see Appendix D).

Outcome

The outcome identified the effects of palliative care RN workflow change on the number of accepted referrals to outpatient palliative care. The communication guide/script included an introduction to palliative care, basic education of palliative care and its reported benefits, and space for the RN to document her assessment of the patient's readiness,

duration of call, questions patients had and acceptance/denial of referral (see Appendix B). The ESAS-r tool and communication guide/script RN training was provided by the PI and took place over the course of one week prior to the start of the workflow change. This EBP project assessed the impact of a workflow change on acceptance rates of palliative care referrals and provided insight into rejections to palliative care referral.

Data Collection

The PI collected prior outpatient palliative care referral data, referral acceptance rates, and demographic data from the most recent eight-week pre-intervention period with assistance from the Epic/Wave IT analytics team. During the eight-week workflow change intervention period, data collection included de-identified patient and demographic information including acceptance or denial of palliative care referral, age, sex, primary diagnosis, disease type/stage, reason why referral was placed, if a caregiver or family is identified or present, if patient was previously referred to palliative care, patient comments, ESAS-r score, duration of call, RN comments, and PI interpretation (see Appendix D). All patient data was de-identified from the nursing script/ESAS-r form and from the EMR.

Protection of Human Subjects/IRB

Exempt Institutional Review Board (IRB) approval was requested and granted by West Chester University of Pennsylvania's (WCUPA) IRB (See Appendix E). Permission to complete EBP project within the PC-ACP program at Sansum Clinic was granted from Sansum Clinic medical director, Dr. Marjorie Newman (See Appendix F). The Institutional Review Board (IRB) approval for West Chester University of Pennsylvania and approval from Sansum Clinic institution associated with the PC-ACP program was obtained in October 2022.

Resources and Personnel

Personnel includes several individuals who participated in carrying out the EBP project. The Principal Investigator (PI) (Stefanie Rashti), external mentor and physician director of the PC-ACP program (Dr. Deborah Meyers), three Palliative Care RNs, Palliative Care coordinator, Sansum Clinic medical director (Dr. Marjorie Newman), and West Chester University of Pennsylvania (WCUPA) faculty mentor (Dr. Marguerite Ambrose). All personnel are in regular contact with the PI for coordination and management of EBP project.

Technology

The RNs received the referral orders to palliative care within Wave/EPIC, the EMR, as well as via fax from outside health care systems and from the local Santa Barbara Cottage Hospital. Patient charts within the EMR were reviewed for appropriateness of referral.

Summary

The focus of this quality improvement project was to increase the number of palliative care referral acceptances. The outcomes of this APRN workflow change may also serve to improve patient and caregiver knowledge of palliative care as well as symptom burden. The PI was responsible for reviewing all outcomes of this project, including results, strengths, limitations, opportunities for improvement, and implications for future practice. Following the project, the PI will present outcomes to direct stakeholders including the PC-ACP team, the physician director, management, and the medical director to reveal statistical findings and review recommendations for potential practice changes or future projects.
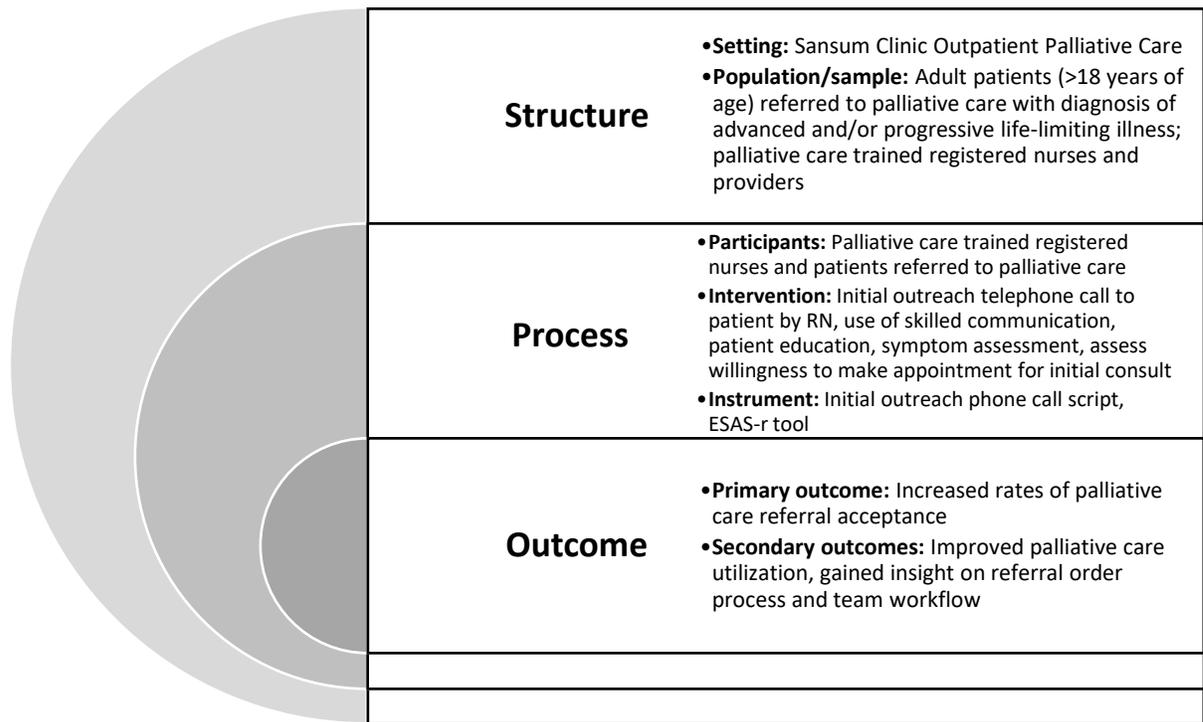
CHAPTER 4

Results

Introduction

The purpose of this QI project was to determine if a workflow change within the outpatient palliative care team at Sansum Clinic would affect referral acceptance rates among patients referred to palliative care. Following approval from the WCUPA IRB and Sansum Clinic medical director, the PI chose the eight-week period, December 5, 2022, through January 27, 2023, to implement the intervention. The workflow changes incorporated RN-led initial outreach telephone calls to patients and/or their caregivers, using the APRN-led telephone call script, assessment, and evaluation form (see Appendix B) and ESAS-r (see Appendix A). Rates of palliative care referrals and referral acceptance were measured during the intervention period, along with patient demographics including age, sex, race and ethnicity, total duration of telephone call, and clinical data including primary diagnosis upon referral, referring provider specialty and reason for referral. This data was analyzed for comparison to the pre-intervention eight-week period, October 10, 2022, to December 2, 2022. The data reviewed from this pre-intervention period revealed a rate of 36.5% of patients agreeing to palliative care referral prior to the workflow change. The Donabedian model was used for this QI project. The data is represented as structure, process, and outcomes (see Figure 1).

Figure 1. Donabedian Model

Structure	• **Setting:** Sansum Clinic Outpatient Palliative Care • **Population/sample:** Adult patients (>18 years of age) referred to palliative care with diagnosis of advanced and/or progressive life-limiting illness; palliative care trained registered nurses and providers
Process	• **Participants:** Palliative care trained registered nurses and patients referred to palliative care • **Intervention:** Initial outreach telephone call to patient by RN, use of skilled communication, patient education, symptom assessment, assess willingness to make appointment for initial consult • **Instrument:** Initial outreach phone call script, ESAS-r tool
Outcome	• **Primary outcome:** Increased rates of palliative care referral acceptance • **Secondary outcomes:** Improved palliative care utilization, gained insight on referral order process and team workflow

Patient Demographics

The average age of patients' pre-intervention and intervention were 72.15 years and 70.59 years respectively, with ages ranging from 27 years to 98 years. Among the pre-intervention patients, 48% reported race as White or Caucasian, 21% other, 19% unknown, 11% refused to state, 0% Black or African American, 0% Asian, and 0% American Indian or Alaska Native (see Table 2). Among the intervention patient populations, 57% reported race as White or Caucasian, 14.6% other, 13% refused to state, 9% unknown, 2% were Black or African American, 2% Asian, and 1% American Indian or Alaska Native (see Table 1). For patients who reported ethnicity, 29% and 35% were non-Hispanic in the pre-intervention and intervention groups respectively, and 15% and 16.8% were Hispanic in the pre-intervention and intervention groups respectively (see Table 1).

Table 1. Patient Demographics

	Pre-Intervention	Intervention
Referrals (total)	52	89
Age (average in years)	72.15	70.59
Sex		
Male	24 (46.2%)	41 (46.1%)
Female	28 (53.8%)	48 (53.9%)
Race		
White	25 (48%)	51 (57%)
Black	0 (0%)	2 (2%)
Asian	0 (0%)	2 (2%)
American Indian & Alaska Native	0 (0%)	1 (1%)
Other	11 (21%)	13 (14.6%)
Unknown	10 (19.2%)	8 (8.9%)
Refused	6 (11.5%)	12 (13%)
Ethnicity		
Hispanic	8 (15%)	15 (16.8%)
Non-Hispanic	15 (29%)	31 (35%)
Other	14 (26.9%)	20 (22.4%)
Unknown	8 (15.5%)	8 (8.9%)
Refused	7 (13.4%)	15 (16.%)

Data Collection

Referral Acceptance Rates

During the pre-intervention period, there were a total of 52 patients referred to palliative care, with a 36.5% acceptance rate. During the intervention period, there were a total of 89 patients referred to palliative care; 54 patients agreed to schedule an initial consult with palliative care provider, with a 60.6% acceptance rate (see Table 2). Of note, upon project completion, 49 of the 89 patients (55.1%) were scheduled or had completed

their initial consult with a palliative care provider, with a total of 5 patients who were unable to schedule in the weeks following the intervention due to hospitalization, transfer to hospice, preferred outpatient palliative care, awaiting insurance to approve referral to palliative care or were unable to reach. This does not change the fact that the acceptance rate was 24.1% higher than pre-intervention.

Table 2. Referral Acceptance

	Pre-Intervention	Intervention
Total # of Referrals Made	52	89
Total # of Referrals Accepted	19 (36.5%)	54 (60.6%)

Referrals

Referrals to palliative care are medical orders placed by health care providers who identify a need for specialized palliative care for their patients. Referrals can be made electronically through the electronic medical record within a patient's chart or via fax if sent by a health care provider within an outside health care system or hospital system. When referrals are made electronically via the EMR, the provider must select "internal referral" button, reason for referral which includes check boxes for the following: pain or symptom management, advance care planning, psychosocial support, home-based care, and other (this is required, providers can check one or all that apply), followed by a comment box where providers can free-text information about the patient they feel is pertinent (see Figure 2). Also included on the referral order but not required is "priority" or how quickly the provider would ideally like the patient to be seen for consultation. A diagnosis code association (labeled as Dx Association) is required prior to signing the referral order (see Figure 3). Referring providers are to select the patient's primary or life-limiting diagnosis, most associated with need for specialty palliative care.

Figure 2. Electronic referral order to Palliative Care

Figure 3. Referral diagnosis code association

Among the pre-intervention group, the majority of patients were referred to palliative care by hematology and oncology providers (53.8%), 13.4% by internal medicine providers, 7.6% by radiation oncology providers, and 27.9% were a mix of multiple specialty providers (see Table 3). Among the post-intervention group, 64% of referring providers to palliative care were from hematology and oncology, 7.8% from radiation oncology, 7.8% internal medicine, 5.6% by family medicine, and 5.6% by pulmonology (see Table 3). Referring diagnoses are broken down by cancer and disease type (see Table 4). The referring diagnoses listed in Table 4 were PI-designated, as some patients had three or more diagnoses listed as their referring diagnoses. The referring diagnosis is the terminal or life-limiting diagnosis most likely requiring specialty palliative care services.

Table 3. Referring Provider Specialty

Referring Provider Specialty	Pre-intervention	Intervention
Anesthesiology	0 (0%)	1 (1.1%)
Cardiology	0 (0%)	2 (2.2%)
Family Medicine	3 (5.7%)	6 (6.7%)
General Surgery	0 (0%)	1 (1.1%)
Hematology and Oncology	28 (53.8%)	58 (65.1%)
Internal Medicine	7 (13.4%)	7 (7.8%)
Neurology	1 (1.9%)	1 (1.1%)
Pain Management	1 (1.9%)	1 (1.1%)
Pulmonology	3 (5.7%)	5 (5.6%)
Radiation Oncology	4 (7.6%)	7 (7.8%)
Rehabilitation Medicine	1 (1.9%)	0 (0%)
Surgical Oncology	1 (1.9%)	0 (0%)
Urology	3 (5.7%)	0 (0%)

(Number of referring providers per specialty)

Table 4. Referring Diagnoses

Referring Diagnosis	Pre-Intervention	Intervention
Cancer		
Brain	3	1
Breast or Gynecologic	4	17
Head and Neck	6	6
Heme, Leukemia, or Lymphoma	5	10
Gastrointestinal	6	23
Genitourinary	8	8
Lung	3	7
Sarcoma	1	1
Skin	2	1
Unknown primary	0	1
Total cancer diagnoses	38	75
Age-related/Debility	2	1
Advanced cardiac disease	0	4
Advanced dementia/neurologic disorder	6	3
Advanced lung disease	1	3
Chronic pain	1	1
End of Life	1	0
ESLD/ESRD	2	1
Multiple or other comorbidities	3	1
Total referrals	52	89

(ESLD = End stage liver disease, ESRD = end stage renal disease, Heme = hematologic)

Reasons for referral are required by the referring provider when placing the initial referral order electronically via the EMR to the palliative care team (see Figure 2). The

reason(s) for referral are checked off electronically and can include one or all that apply, with most providers requesting assistance with pain and symptom management; 42 out of 52 referrals for the pre-intervention group and 66 of our 89 referrals for the post-intervention group (see Table 5). Advance care planning and psychosocial support are also prominent requests.

Table 5. Reason for Referral

	Pre-intervention	Intervention
Pain and Symptom Management	42	66
Advance Care Planning	23	43
Psychosocial Support	26	56
Home Based Care	9	6
Other	4	5

Comments included on the electronic referral orders from referring providers were made via free-text and included request for assistance with pain and symptom management, assistance with goals of care discussions and completion of advance directive, existential, emotional, and spiritual distress, end of life questions, complicated family dynamics, medication management, and patient interest in End-of-Life Option Act (see Figure 2).

ESAS-r scores

Throughout the intervention period, the ESAS-r tool was used by the RNs during initial outreach telephone calls to patients referred to palliative care to help guide conversation and to assist in identifying and evaluating symptom burden and severity (Nekolaichuk et al., 2019) (see Appendix A). The ESAS-r is comprised of ten commonly reported symptoms, ranging from 0 (no symptom) no 10 (worst possible) (Hui & Bruera, 2017). The patient's symptom receives a 0 if no symptom is present, mild symptoms range from 1-3 out of 10, moderate symptoms range from 4-6 out of 10, and severe symptoms range from 7-10 out of 10. Of the 89 total referrals made during the intervention period, the

nurses were successfully able to speak to 69 patients or caregivers via telephone. During these conversations, a total of 50 ESAS-r screenings were completed. A total of 19 ESAS-r screenings were not complete due to time constraints of RN, patient refusal or inability to complete due to cognitive impairment, lack of privacy, or not feeling well during the time of the call.

The total ESAS-r score is referred to as the symptom distress score (SDS), which includes a total of all 10 ESAS-r variables with a maximum score of 100. The average SDS for patients in the intervention group was 34.24 out of a total of 100 points (see Table 6). Patients who agreed to initial consult and completed the ESAS-r, had a slightly higher average SDS equaling 37.13/100. Average pain score for all patients was 3.97/10, fatigue score 5.35/10, nausea score 1.68/10, depression score 3.58/10, anxiety score 3.73/10, drowsiness score 3.16/10, shortness of breath score 2.46/10, appetite score 3.66/10, feeling/wellbeing score 3.74/10, sleep score 3.88/10. For patients who accepted initial consult their scores were slightly higher in all categories; pain score 4.36/10, fatigue score 5.81/10, nausea score 1.86/10, depression score 3.86/10, anxiety score 4.03/10, drowsiness score 3.4/10, shortness of breath score 2.73/10, appetite score 3.6/10, feeling/wellbeing score 4.03/10, sleep score 4.25/10. The average fatigue score was highest compared to all symptoms. All average symptom scores ranged from mild to moderate symptom burden, as they ranged between 1 to 6 out of 10.

Table 6. ESAS-r scores

Symptom	Average symptom score for all referred patients	Average symptom score for those who agreed to initial consult
Pain	3.97/10	4.36/10
Fatigue	5.35/10	5.81/10
Nausea	1.68/10	1.86/10
Depression	3.58/10	3.86/10
Anxiety	3.73/10	4.03/10
Drowsy	3.16/10	3.40/10
Shortness of Breath	2.46/10	2.73/10
Appetite	3.66/10	3.90/10
Feeling/Wellbeing	3.74/10	4.03/10
Sleep	3.88/10	4.25/10
Total Symptom Distress Score (SDS)	34.24/100	37.13/100

Initial outreach telephone calls

Of the 89 patients referred to palliative care during the intervention period, 84 patients were contacted via telephone by the RNs. Of the patients the RNs were able to call during the intervention period, there were a total of 15 of the total 84 patients called that the RNs were unable to reach. If possible, a voicemail was left explaining the reason for the call, and a brief note was documented in the patient's EMR noting that a telephone call was made and forwarded to the EMR nursing inbox for further follow up. For time purposes, a total of two outreach telephone calls were made within one to two weeks and a written letter were mailed to the patient explaining that a palliative care referral had been made with hopes to schedule an initial consultation, along with contact information for the palliative care team.

The RNs were able to reach and speak to 69 total patients and/or caregivers via telephone during the intervention period. The duration of the initial outreach telephone calls was documented 43 out of the total 69 conversations completed. The average length of call was 27.5 minutes, with call time ranging from 4 minutes to 65 minutes amongst all patients.

For patients who declined the referral in the intervention period, the average length of telephone call was 11 minutes; for those who accepted the referral, the average length of telephone call was 25 minutes. There were five Spanish speaking patients that required the clinical coordinator (who is the only bilingual, Spanish speaking palliative care staff member) to make these calls.

Patient/Caregiver Comments

The PI reviewed all documentation from the data collection sheets and focused on the specific comments recorded by the RNs. Themes emerged from patient and caregiver comments made to the RN during the initial outreach telephone call which included: a sense of relief, misconceptions and fears, financial concern or time constraint, and uncertainty or unawareness of palliative care or palliative care resources (see Table 7 for direct quotes from patients/caregivers).

Table 7. Patient/Caregiver Comments

Themes	Patient and/or Caregiver Comments
Sense of relief	"I wish we had this referral sooner." (C) "I'm glad to have someone following me." (P) "Delighted to receive support." (P)
Misconceptions and fears	"Does this mean I'm dying?" (P) "Is this hospice?" (C) "You better not be hospice." (C)
Financial concern or time constraint	"Does my insurance coverage take care of this?" (P) "I have too many doctor visits right now." (P)
Uncertainty	"Palliative care referral was not really explained by my doctor." (P) "Why do I need this? (P)

(C= caregiver, P= patient)

Conclusion

The data shows an improvement in palliative care referral acceptance rates from 36.5% in the pre-intervention period to 55.1% in the post-intervention period. Due to RN time constraints and workflow changes with the coordinator working remotely during the intervention period there were gaps in data collection and delays in scheduling of initial consultations. Despite workflow and staffing challenges, the post-intervention period noted an increase of 24.1% in referral acceptances.

CHAPTER 5

Discussion

Review of the problem

This QI project sought to determine if a change in workflow within the outpatient palliative care team at Sansum Clinic would influence referral acceptance rates in adult patients referred to the palliative care team. The outcome of this project supports the literature emphasizing the importance of advanced communication skills and how the delivery of palliative care education provided by professionally trained registered nurses can positively impact and influence the care of patients with serious illness (Hagan et al., 2018; Hay et al., 2017; Hoerger et al., 2017, Kirby et al., 2014). Key findings include a 24.1% increase in referral acceptance rates with the incorporation of palliative care board-certified nurses into the initial outreach process for patients referred to palliative care.

There were no significant differences between average age of the patient, percentage of males versus females, race or ethnicity between pre-intervention and intervention groups. In the intervention group, patients who agreed to an initial consult and completed the ESAS-r (see Appendix A), had a slightly higher average SDS. Results from the ESAS-r revealed an average patient symptom score ranging from 1-5/10 with fatigue scoring the highest amongst patients at 5.81/10. This indicates that fatigue was the most distressing symptom for patients referred to palliative care, independent of their disease or cancer type. In the intervention group, for patients who accepted the referral, the average duration of telephone call was 14 minutes longer, indicating that patients with higher symptom burden required longer discussion.

Interdisciplinary palliative care and supportive medicine teams provide specialized medical care that focus on improving pain and symptom management, advance care planning and goals of care discussions, and providing emotional, spiritual, and psychosocial support for patients and their families (Hagan et al., 2018; Meier & McCormick, 2022). Project findings supported the literature as patients were mainly referred to palliative care for pain and/or symptom management, advance care planning and psychosocial support. Comments included on the electronic referral orders from referring providers also included requests to assist with goals of care discussion and advance directive, existential, emotional, and spiritual distress, end-of-life questions, decision making, and patient interest in the End-of-Life Option Act (California's term for Death with Dignity).

Themes that unfolded from patient and caregiver comments during the initial outreach telephone call supported barriers to palliative care referrals as noted in the literature (Dosani et al., 2020; Flieger et al., 2020; Maciasz et al., 2013; McVeigh et al., 2019; Paiva et al., 2020; Saretta et al., 2022; Steiger et al., 2020; Zimmermann et al., 2016). These barriers included patient and caregiver misconceptions and fears, that palliative care equates with hospice care, death or dying, uncertainty, lack of knowledge of palliative care, time constraints and financial concerns. There was also a sense of relief from patients and caregivers as many were grateful for additional care team members and support.

The pre-intervention group had a much lower total number of referrals during the eight-week period, with 37 less referrals. There was an increase in referrals made by referring providers during the intervention period (December 5, 2022-January 27, 2023). Patients may have reported higher symptoms burden or exhibited more emotional distress during this time.

RN Comments

The RNs provided written comments on their initial outreach telephone call script/evaluation forms during and following telephone calls. Review of the RN comments and post-intervention debriefing discussions led to the following themes: lack of awareness or misconceptions of palliative care, time constraints, and enjoyment of more team-based approach to palliative care. RNs felt that approximately half of the referred patients knew about palliative care or were aware of the referral order. Several required full explanations of palliative care versus hospice, and many knew they were referred to palliative care but did not know the full scope of palliative care resources. RNs felt the task of reviewing patients' charts and calling patients should be tailored to one RN as they felt outreach phone calls became challenging along with normal triage telephone calls and work tasks throughout the day. The RNs liked being able to "meet" the patient and families virtually, introduce the palliative care team, and use their nursing assessment and education skills. RNs also learned that referrals were also ordered from outside healthcare systems and the local hospital via fax and were not appearing on the electronic referral queue like internal electronic referrals within Sansum Clinic.

PI Interpretation

The PI was a direct recipient of referrals, as well as the palliative care physician director. Anecdotal evidence from the PI and physician director revealed that the ESAS-r scores generated during the initial outreach telephone call, along with RN comments, inspired conversation and focus on symptom management during the initial, in-person consultation visit. There were a few workflow-related items that were not obvious before the

QI project, that were highlighted during the intervention period and data collection phases. The team learned how referrals were made by referring providers, at times with useful comments and stated objectives for how they hope palliative care can assist in the patient's care. The PI had to make interpretations of referring diagnoses, as several diagnoses (three or more) were often selected along with the referring order, and the most severe or life-limiting illness was not always labeled first. The team also learned that the referral outreach process can be time consuming and requires diligent oversight.

Limitations of the Project

There was no control group or randomization within the project. There was also no clear way to statistically compare the pre-intervention and intervention groups as there were different palliative care team members leading the patient outreach telephone calls in each group (the coordinator in the pre-intervention setting versus RN in the intervention setting), and no script or symptom assessment (ESAS-r) was used by the coordinator in the pre-intervention period. The PI made interpretations of referring diagnoses and what referral objectives were as the objective on the electronic referral order was not always well-defined. Staffing was a limitation for the duration of project as the coordinator worked remotely due to personal reasons. The initial outreach telephone call often took place over two calls; one where the nurse introduced the palliative care team, provided education and symptom assessments, followed by a separate coordinator telephone call, where the patient was able to schedule their initial consultation appointment with a provider. This, at times, caused a delay in scheduling. An additional limitation was the fact that there were three different RNs calling patients, each with a unique skill set and personality, years of working experience,

and education background (although all in nursing, or with palliative care or oncology board certifications). And lastly, the intervention period was short (only 8 weeks in duration).

Implications for Nursing Practice, Education, and Research

Nursing Practice

The method for initial patient outreach has always been via telephone call, and for patients who do not answer, a voicemail is left indicating a reason for the call. Since the patient has not established a relationship with the palliative care team members prior to referral, hearing the term "palliative care", without the proper education, may leave patients or caregivers feeling unsettled, upset, or confused. The literature supported this, with the term "supportive care" used instead of palliative care to help decrease stigma and fears and was deemed a more favorable term (Maciasz et al., 2013). This language was incorporated into the definition of palliative care used by nurses within the initial outreach telephone call script (see Appendix B). If hearing the term palliative care may be upsetting or lead to uncertainty, it leads the question if placing a telephone call or leaving a voicemail to introduce the palliative care team is the correct modality of outreach. Should the initial palliative care outreach discussion take place in person whenever possible? Presently, when time permits, the palliative care RNs meet patients following an oncology visit or within the infusion suite if the patient is receiving care within the Cancer Center to introduce the palliative care team or to provide a nursing assessment.

Embedding a palliative care trained RN into oncology visits to help educate and assess for symptom burden may help to ease patients' discomfort, meet a friendly and nurturing palliative care team member, and may help to improve referral acceptance rates. For time and staffing reasons at present, this workflow is not possible on a daily basis, nor

would this be feasible for other specialties within Sansum clinic offices around the town. However, it may be something to consider as a future clinical opportunity to improve referral acceptance rates.

The majority of patients referred to palliative care were by oncology-trained providers (including hematology/oncology, radiation, and surgical oncology). The palliative care team is embedded within the Ridley-Tree Cancer Center, making a referral to this supportive care service easier for oncology providers to remember as they have greater access to the team physically. Future work to establish relationships and increase palliative care education to other specialty providers within the clinic is paramount to provide greater access to patients diagnosed with non-oncologic advanced diseases with increasing symptom burden or need for advance care planning.

Nursing and Healthcare Provider Education

According to Carey and colleagues (2019), barriers to the delivery of primary palliative care delivery by primary care providers includes lack of skills and confidence, lack of time, personal commitments, and communication between health care professionals. Enablers or facilitators to the delivery of primary palliative care includes education, nursing, and trained support staff to assist in care coordination and delivery, as well as communication between providers (Carey et al., 2019). This supports the implementation of palliative care education and integration of palliative care staff into outpatient primary care and specialty offices. With further education, support, and ability to provide care coordination, it may empower providers to engage in and deliver primary palliative care to their patients or refer more often to specialty palliative care when appropriate.

Future efforts should be made to educate nurses and supportive staff within the specialty of oncology to identify patients who could benefit from palliative care earlier, provide education to patients and caregivers to decrease fears and misconceptions, and encourage providers to place referrals. Following the results and analysis of this DNP project, the PI and physician director have had discussions with oncology colleagues to discuss project findings and to encourage dissemination of previously developed palliative care informational handouts during chemotherapy teaching sessions, to help better explain the supportive care services involved and introduce the palliative care team.

Nursing Research

There are many potential future research opportunities that have stemmed from the completion of this DNP project. Future research should be done to modify or improve the electronic referral order to highlight the true objective of the referral by the referring provider. Additional research could be conducted to further assess patient attrition and how long patients remain on the palliative care team prior to death. This may help to determine if referrals to palliative care are being made earlier on or late in a patient's illness trajectory. Research could also be conducted to determine if greater incorporation of symptom assessment tools, such as the ESAS-r, helps to streamline patient visits and better prepare the palliative care providers for the initial consultation with the referred patient. It would also be interesting to assess how patient and caregivers responded to the palliative care consult; if their pain, symptoms, quality of life, and other psychosocial factors were improved following one or more visits with the palliative care team, and if these factors differ between those who accept the palliative care consult and those who declined. Future research to evaluate effects of an embedded or integrated palliative care trained nurse or

professional on palliative care measures within outpatient oncology, primary care and other specialty offices is also encouraged.

Conclusion

There was a significant increase in referral acceptance rates during the intervention period. Future endeavors to explore the incorporation of palliative care trained nurses within the referral outreach process should be done as their skills may help to reduce fears, dispel myths, educate patients, provide psychosocial support at a challenging time, and to make critical symptom assessments to help guide the palliative care provider during their initial consultation with the referred patient. Despite the current challenges at Sansum Clinic, every effort will be made to ensure patients referred for palliative care will receive earlier education, quality care, and support from our team members.

Unfortunately, following the conclusion of the intervention period, one of the three palliative care RNs resigned. Due to financial constraints within the Sansum Clinic healthcare system, the RN position will not be replaced. The outcomes of this QI project demonstrate the effectiveness of an RN conducting the initial outreach and the increase in referral acceptance rates and palliative care utilization. With greater referral acceptance and palliative care utilization, it may lead to an increase in revenue from a cost perspective for the healthcare system, and improved quality of life, patient satisfaction, and decrease in symptom burden from a quality and outcomes perspective.

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Appendix A

Edmonton Symptom Assessment System-revised (ESAS-r)

Date:_____ Time: _____

Please circle the number that best describes your average symptom over the past 24 hours:

No Pain	0 1 2 3 4 5 6 7 8 9 10	Worst Pain
No Fatigue	0 1 2 3 4 5 6 7 8 9 10	Worst Fatigue
No Nausea	0 1 2 3 4 5 6 7 8 9 10	Worst Nausea
No Depressed	0 1 2 3 4 5 6 7 8 9 10	Worst Depression
Not Anxiety	0 1 2 3 4 5 6 7 8 9 10	Worst Anxiety
No Drowsiness	0 1 2 3 4 5 6 7 8 9 10	Worst Drowsiness
No Shortness of Breath	0 1 2 3 4 5 6 7 8 9 10	Worst Shortness of Breath
Best Appetite	0 1 2 3 4 5 6 7 8 9 10	Worst Possible
Best Feeling or Well Being	0 1 2 3 4 5 6 7 8 9 10	Worst Feeling of Well Being
Best Sleep	0 1 2 3 4 5 6 7 8 9 10	Worst Sleep

Completed by: ☐ Patient ☐ Family

Assessed by (Signature/Credentials/ID#/ Date/ Time)_____

Print / Stamp Name: _____

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Appendix B

Initial Outreach Telephone Call Script, Assessment and Evaluation

Patient MRN:
Patient Identifier:
Date:
Primary disease/illness as listed on referral order:
Reason for referral as listed on referral order:
Communication: with patient _____ OR caregiver _____

Hello, this is _____ from the Palliative Care and Advance Care Planning Team at the Ridley-Tree Cancer Center at Sansum Clinic.

On _____ (date), you met with _____NP/PA/MD, who placed a referral for Palliative Care.

You have been referred to Palliative Care to help you manage _____ (as listed on referral order). Are you aware this referral was placed?

The purpose of this call is to introduce our palliative care team, assess any symptoms you may have and schedule you for an initial visit with one of our providers.

What is palliative care?

Our palliative care team provides specialized medical care and an additional layer of support for you, your family and caregivers. Our goal is to improve pain, symptoms, quality of life and manage stressors that you may be experiencing related to your illness. We also assist in coordination of care, decision making regarding complex medical issues, with advance care planning, as well as collaborate closely with your oncologist or specialty providers.

Palliative care also helps patients improve their ability to tolerate medical treatments, better understand their choices for care and provides support to families and caregivers. We work to customize treatment to meet the needs of each individual patient.

If patient asks, what is advance care planning?

Advance care planning services include support in exploring your values, goals, beliefs and healthcare preferences, understand your current health care status and expected course of illness, select a qualified health care agent to act on your behalf, document health care agent

and preferences in an advance directive and share decisions with loved ones and health care providers.

If patient asks, what is the difference between palliative care and hospice?

Palliative care is designed to relieve suffering and improve quality of life, to help patients continue with daily living. It is provided while treatment is being delivered and is available at any time during a patient's illness. Hospice also provides palliative care but is focused on patients who no longer seek a cure for their illness and who are expected to live for about six months or less.

I would like to ask you some questions regarding some symptoms that you may be experiencing to see how things may have changed since you last saw _____ (referring provider). This will be helpful so our team can work to manage and/or improve pain/symptoms and improve your overall quality of life.

Edmonton Symptom Assessment System-revised (ESAS-r)

Date:_____ Time: _____

Please circle the number that best describes your average symptom over the past 24 hours:

No Pain	0 1 2 3 4 5 6 7 8 9 10	Worst Pain
No Fatigue	0 1 2 3 4 5 6 7 8 9 10	Worst Fatigue
No Nausea	0 1 2 3 4 5 6 7 8 9 10	Worst Nausea
No Depressed	0 1 2 3 4 5 6 7 8 9 10	Worst Depression
Not Anxiety	0 1 2 3 4 5 6 7 8 9 10	Worst Anxiety
No Drowsiness	0 1 2 3 4 5 6 7 8 9 10	Worst Drowsiness
No Shortness of Breath	0 1 2 3 4 5 6 7 8 9 10	Worst Shortness of Breath
Best Appetite	0 1 2 3 4 5 6 7 8 9 10	Worst Possible
Best Feeling or Well Being	0 1 2 3 4 5 6 7 8 9 10	Worst Feeling of Well Being
Best Sleep	0 1 2 3 4 5 6 7 8 9 10	Worst Sleep

Completed by: ☐ Patient ☐ Family

Assessed by (Signature/Credentials/ID#/ Date/ Time)_____
Print / Stamp Name: _____

Important to note that private insurance, Medicare and Medicaid cover costs for Palliative Care visits like your primary care or specialist visits.

In conclusion, our hopes are to schedule an appointment for your initial consult with one of our palliative care providers. May I transfer you to our administrative assistant/coordinator who can assist in making that appointment?

Patient agrees to referral: Yes _____ No _____

If no, reason why? _____

To patient/caregiver, "May I call you back in a week to check in on your symptoms?"

Patient agrees to follow up call _____.
If disagrees, "May I ask why?"

RN Notes:

Duration of call (minutes): _____

Appendix C

ESAS-r Tool Permission Request

M Gmail   **Stefanie Rashti**   @gmail.com

ESAS-r tool permission request

Viki Muller   Sun, Oct 16, 2022 at 3:56 PM
To: Stefanie Rashti

Hi Stephanie

A formal letter is not sent with the request for use.

We use the information for tracking and research purposes. The tool is in the public domain and does not require formal approval.

All the best with your initiative

Viki

From: Stefanie Rashti
Sent: Sunday, October 16, 2022 3:18 PM
To: palmed@ualberta.ca
Subject: ESAS-r tool permission request

Caution - This email came from an external address and may contain unsafe content. Ensure you trust this sender before opening attachments or clicking any links in this message

To whom this may concern,

I recently submitted the online permission request form for use of the ESAS-r tool. Is it possible for you to send an approval letter, with permission to use the tool once you have reviewed my request?

Thank you,

Stefanie Rashti

This message and any attached documents are only for the use of the intended recipient(s), are confidential and may contain privileged information. Any unauthorized review, use, retransmission, or other disclosure is strictly prohibited. If you have received this message in error, please notify the sender immediately, and then delete the original message. Thank you.

Appendix D

PI Data Collection Sheet

Patient ID (P1, P2, ...)	Date	RN	Agree to consult? ('Age	Sex	Race	Ethnicity	Primary Diagnosis	Referred for?	Identified caregiver	ESAS-r score	SDS	Pt comments	RN Comments	PI Interpretation	Duration of call

Column headers of PI Data Collection Sheet and corresponding number references for purposes of data analysis:

- Patient ID (P1, P2, P3…)
- Date of outreach telephone call
- RN making outreach telephone call (RN 1, RN 2, RN 3)
- Agree to consult? (Yes=1, No= 2)
- Age
- Gender (Female =1, Male =2)
- Referred for? (Pain or symptom management = 1, , psychosocial support = 2, advance care planning = 3, other = 4)
- Primary diagnosis (Brain cancer =1, breast or gynecologic cancer = 2, head and neck cancer = 3, hematologic malignancy, leukemia or lymphoma = 4, gastrointestinal cancer = 5, genitourinary cancer = 6, lung cancer = 7, lung cancer = 8, sarcoma = 9, skin cancer = 10, unknown primary cancer = 11, age-related/debility = 12, advanced cardiac disease = 13, advanced dementia or neurologic disorder = 14, advanced lung disease = 15, chronic pain = 16, end-of-life = 17, ESLD or ESRD = 18, multiple or other comorbidities = 19)
- Identified caregiver or family (Yes = 1, No = 2)
- Previously referred to Palliative Care (Yes = 1, No = 2)
- Patient Comments
- ESAS-r individual symptom scores
- Total Symptom Distress score (SDS)
- Duration of call
- RN Comments
- PI Interpretation

Appendix E

West Chester University of Pennsylvania Institutional Review Board Approval Letter

Office of Research and Sponsored Programs | West Chester University | Ehinger Annex
West Chester, PA 19383 | 610-436-3557 | www.wcupa.edu

Oct 31, 2022 1:08:44 PM EDT

To: Stefanie Rashti
Department: School of Nursing, Nursing

Re: Exempt - Initial - IRB-FY2023-97 The Impact of an APRN Directed Workflow Change on Outpatient Palliative Care Referral Acceptance Rates

Dear Stefanie Rashti:

Thank you for your submitted application to the WCUPA Institutional Review Board. We have had the opportunity to review your application and have rendered the decision below for The Impact of an APRN Directed Workflow Change on Outpatient Palliative Care Referral Acceptance Rates .

Decision: Exempt

Selected Category: Category 4. Secondary research for which consent is not required: Secondary research uses of identifiable private information or identifiable biospecimens, if at least one of the following criteria is met:
    (i) The identifiable private information or identifiable biospecimens are publicly available;
    (ii) Information, which may include information about biospecimens, is recorded by the investigator in such a manner that the identity of the human subjects cannot readily be ascertained directly or through identifiers linked to the subjects, the investigator does not contact the subjects, and the investigator will not re-identify subjects;
    (iii) The research involves only information collection and analysis involving the investigator's use of identifiable health information when that use is regulated under 45 CFR parts 160 and 164, subparts A and E, for the purposes of "health care operations" or "research" as those terms are defined at 45 CFR 164.501 or for "public health activities and purposes" as described under 45 CFR 164.512(b); or
    (iv) The research is conducted by, or on behalf of, a Federal department or agency using government-generated or government-collected information obtained for nonresearch activities, if the research generates identifiable private information that is or will be maintained on information technology that is subject to and in compliance with section 208(b) of the E-Government Act of 2002, 44 U.S.C. 3501 note, if all of the identifiable private information collected, used, or generated as part of the activity will be maintained in systems of records subject to the Privacy Act of 1974, 5 U.S.C. 552a, and, if applicable, the information used in the research was collected subject to the Paperwork Reduction Act of 1995, 44 U.S.C. 3501 et seq.

If there are any questions, please don't hesitate to reach out to irb@wcupa.edu

Sincerely,
WCUPA Institutional Review Board

IORG#: IORG0004242
IRB#: IRB00005030
FWA#: FWA00014155

Appendix F

Sansum Clinic Approval Letter

sansum^{SM} CLINIC

October 17, 2022

Dear Sir/Madam,

I am writing this letter on behalf of Stefanie Rashti, CRNP who is a valued member of Sansum Clinic's Palliative Care Department. As you know, Ms. Rashti is enrolled in the West Chester University of Pennsylvania DNP program and she has shared her DNP Project proposal with members of our palliative care team and with clinic leadership and we are supportive of her project titled, *The Impact of an APRN Directed Workflow Change on Outpatient Palliative care Referral Acceptance Rates.*

The project is focused on changing and ultimately enhancing the work flows regarding outreach phone calls to patients who are referred to the palliative care program, with the goal of improving the initial patient and caregiver education outlining the role of palliative care and improving acceptance of palliative care appointments by those who would greatly benefit from this service.

Ms. Rashti's project can be executed at her place of employment and can occur during her regular work/administrative hours with her current role and patient population. Since this is a quality improvement project with no sharing of patient health information, it does not require IRB approval.

We are looking forward to seeing how these enhanced outreach efforts will enhance the care provided to our patients.

Please don't hesitate to reach out if I can answer any additional questions.

Sincerely,

Marjorie Newman MD
Medical Director
(805)681-1866
mnewman@sansumclinic.org