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EARLY INTEGRATION OF PALLIATIVE CARE WITH CURATIVE ONCOLOGY

TREATMENT FOR PATIENTS WITH ADVANCED CANCER:

IMPLICATIONS FOR CLINICAL NURSING PRACTICE

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Abstract

Palliative care, though clinically established to improve health-related quality of life measures for patients with advanced illness, remains underutilized and largely limited to end of life care. This project aims to inform oncology nursing practice through the analysis of literature supporting the early integration of palliative care with standard curative oncology treatment for patients with clinically advanced cancer. Informed by relevant research, clinical practice guidelines, and improved specialty palliative care training, oncology nurses and nurse practitioners are ideally situated to advocate for and initiate early palliative care integration, to holistically improve the standard approach to complex cancer care.

Introduction

Palliative care is simultaneously a philosophy of care and a highly structured system for care delivery that aims to improve the quality of life for any patient with advanced, serious illness. Yet global data from the World Health Organization (WHO) indicates that only an estimated 14% of patients who need palliative care receive it (World Health Organization, 2020). Palliative care is conceptually broader than hospice care, which is reserved for patients with terminal illness, defined by a life expectancy of six months or less (Medicare, n.d.). Unlike hospice care, palliative care can be utilized in conjunction with curative treatment that seeks to prolong life (National Hospice and Palliative Care Organization, n.d.). Furthermore, palliative care principles can be incorporated into the care of any patient, with any serious illness, with any prognosis, in any clinical setting (National Hospice and Palliative Care Organization, n.d.).

In 2004, the National Consensus Project for Quality Palliative Care, a coalition of the Hospice and Palliative Nurses Association (HPNA), the American Academy of Hospice and Palliative Medicine (AAHPM), the National Hospice and Palliative Care Organization

(NHPCO), and the Center to Advance Palliative Care (CAPC), developed and published the first clinical practice guidelines to define a foundation for the delivery of standardized, high-quality palliative care. Current guidelines define palliative care as “an interdisciplinary care delivery system designed to anticipate, prevent, and manage physical, psychological, social, and spiritual suffering to optimize quality of life for patients, their families and caregivers... [through] expert assessment and management of pain and other symptoms, assessment and support of caregiver needs, and coordination of care” (National Consensus Project for Quality Palliative Care, 2018). A timeframe for the the provision of palliative care is intentionally unspecified in this definition. Considering that palliative care is appropriate at any stage in serious illness, a timeframe for the the provision of palliative care is intentionally unspecified in this definition. However, the guidelines notably cited the “2015 Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life” report, which indicated that care outcomes (namely quality of life and severity of pain) were optimized when palliative care was implemented soon after diagnosis of a serious condition, and delivered simultaneously with curative or disease-modifying treatments (Institute of Medicine, 2015).

The prevalent misconception that palliative care is synonymous with hospice care contributes to an underuse of palliative care principles and specialty referral for patients with serious illnesses, such as advanced cancer, that may benefit from holistic care approaches. Oncology patients frequently develop devastating physiologic and psychosocial symptoms (notably anorexia, pain, fatigue, dyspnea, delirium, and depression), as well as functional decline, spiritual and emotional distress, and financial concerns (Bruera & Hui, 2010). Cancer patients and their families often require counseling and education about clinical diagnoses and care plans, discussion regarding goals of care, and advanced care planning (Bruera & Hui, 2010),

all of which are elements addressed through palliative care. Despite clinical research studies linking palliative care with improved outcomes for cancer patients, standard palliative care implementation is still underutilized and often limited to the terminal phase of illness for this patient population (Haun et al., 2017). This notion may be exacerbated by healthcare professionals' inadequate training on palliative care practices, limited competency of palliative care practice guidelines, and deficient comfortability utilizing these principles in clinical practice (Zimmermann et al., 2014).

Research Objective

This project aims to inform oncology nursing practice through the analysis of literature and clinical guidelines supporting the early integration of palliative care with standard curative oncology treatment for patients with advanced cancer. Through clinical research dissemination, the clarification of clinician's roles in palliative care delivery models, and the expansion of specialty training in medical and nursing schools, we may revolutionize the standards of care for patients with advanced cancers. Early integrated palliative care offers opportunities for oncology patients and caregivers to deeply consider the implications of prognosis and meaningfully participate in care. Furthermore, early integrated palliative care offers opportunities for healthcare providers, including oncology nurses and nurse practitioners, to align prescribed treatment plans with patient goals of care, alleviate undue suffering, and effectively honor human dignity at every stage of illness, including the end of life.

Relevant Literature Review

The authors of an intervention review published in the 2017 Cochrane Database of Systematic Reviews aimed to examine the influence of early palliative care on health outcomes for patients with advanced, incurable cancer, considering the ambiguous effects of late palliative

care (Haun et al., 2017). The authors compared the findings of seven randomized control trials (RCTs) and cluster-randomized control trials (c-RCTs) in which cancer patients were offered either palliative care during or shortly after the time of diagnosis, or standard oncologic care (in which palliative care was only offered towards the end of life). In both intervention groups, patients continued receiving oncologic treatments intended to be curative, such as chemotherapy and radiation. Care provided to the early palliative care group, either by the attending oncologist or specialist care teams depending on the study, emphasized therapeutic patient/clinician communication regarding patient prognosis and implications on quality of life, advance care planning, and symptom assessment and control. The reviewers focused on the primary outcomes of health-related quality of life, depression, symptom intensity, and survival for the two intervention groups. Synthesis of data from a collective sample size of 1,028 participants indicated that patients who received the early palliative care intervention reported significantly higher quality of life (Standardized Mean Difference 0.27) than patients who received standard oncology care. The data analysis yielded non-significant differences in survival rates (Death Hazard Ratio 0.85) and depressive symptoms (Standardized Mean Difference -0.11) between the two subject groups (Haun et al., 2017). However, the early palliative care patients did report slightly lower symptom intensity (Standardized Mean Difference -0.23) than the standard oncology care patients (Haun et al., 2017). The preceding analysis of studies included in this review will interrogate these findings and their implications on clinical oncology practice.

One RCT included in the Haun et al. (2017) review studied the influence of a nurse-led, palliative-care focused intervention concurrent with standard oncologic care, entitled Project ENABLE (Educate, Nurture, Advise, Before Life Ends), on the outcomes of patients with advanced cancer (Bakitas, Doyle Lyons, Hegel, Balan, Brokaw, et al., 2009). The intervention,

conducted by specialty-trained palliative care advanced practice registered nurses (APRNs), consisted of four initial structured educational and problem-solving sessions followed by monthly telephone follow-up sessions until patient death or conclusion of the study. The APRNs utilized assessment tools to identify, prevent, and alleviate suffering, provided coaching on problem-solving, family and healthcare team communication strategies, advance care planning, symptom management, crisis prevention, and referral to hospice services. The researchers hypothesized that patients diagnosed with life-limiting cancer (prognosis of approximately one year) randomly assigned to this intervention would grow into “informed, active participants in their care and would experience improved quality of life and mood, symptom relief, and lower resource use over the course of the illness, including at the very end of life compared with patients who received usual care” (Bakitas, Doyle Lyons, Hegel, Balan, Brokaw, et al., 2009). Longitudinal statistical analyses for the total sample of 279 participants revealed higher quality of life ($p = 0.02$) (measured by the Functional Assessment of Chronic Illness Therapy for Palliative Care scores) and lower depressed mood ($p = 0.02$) (measured by the Center for Epidemiological Studies Depression Scale) for the patients in the intervention group after 13 months of study (Bakitas, Doyle Lyons, Hegel, Balan, Brokaw, et al., 2009). There were no statistically significant differences in symptom intensity (measured by the Edmonton Symptom Assessment Scale [ESAS]), resource utilization (namely days in the hospital or emergency department visits), or survival rates between the groups (Bakitas, Doyle Lyons, Hegel, Balan, Brokaw, et al., 2009). Considering the significant improvements in quality of life and mood associated with the early implementation of the palliative care intervention focused on addressing physical, psychosocial, and care coordination, the researchers maintained that

palliative care concurrent with standard oncologic care holds potential for improved clinical outcomes for advanced cancer patients.

A phase III, RCT cited by Haun et al. (2017) established support for early palliative care specifically for patients with metastatic non-small cell lung cancer, the leading cause of death from cancer worldwide (Temel et al., 2010). Study participants (patients diagnosed with metastatic non-small cell lung cancer within the previous eight weeks) were randomly enrolled to receive early palliative care integrated with standard oncologic care or solely standard oncology care, supplemented by palliative care only if requested by the patient, family, or attending oncologist. The patients in the intervention group met with either a palliative care physician or advanced-practice nurse within three weeks of enrollment, and monthly thereafter in the outpatient setting until death. The palliative care team focused on assessing physical and psychosocial symptoms, establishing goals of care, assisting with treatment-centered decision making, and coordinating care, as guided by the National Consensus Project for Quality Palliative Care. The primary outcome compared at baseline and 12 weeks was the Trial Outcome Index (TOI), the sum of sub scores for physical well-being, functional well-being, and lung cancer symptoms measured by the Functional Assessment of Cancer Therapy-Lung (FACT-L) scale. Additional data was collected on patient mood (Hospital Anxiety and Depression Scale [HADS] and Patient Health Questionnaire 9 [PHQ-9]) and use of health services (namely anticancer therapy, prescribed medications, referral to hospice, hospital admission, and emergency department visits as documented in the electronic medical record). Data collected from a total of 151 study participants indicated that the patients enrolled in the early palliative care group reported significantly higher quality of life scores at 12 weeks ($p = 0.04$) than patients in the standard oncologic care group (Temel et al., 2010). There were also fewer patients

diagnosed with depression in the early palliative care group ($p = 0.01$; $p = 0.04$), despite similar proportions of antidepressant prescriptions reported among the two groups (Temel et al., 2010). The patients in the early palliative care group received significantly less aggressive end of life care ($p = 0.05$) than the patients in the standard oncologic care group (Temel et al., 2010). Though palliative care can be utilized in conjunction with aggressive care, this study found that the early introduction of palliative care led to a reduction of chemotherapy and longer hospice care. Interestingly, despite receiving less aggressive end of life care patients in the early palliative care group survived 2.7 months longer than the patients in the standard oncologic care group ($p = 0.02$) (Temel et al., 2010). Though survival rates were not the primary outcome of this study, this finding has relevant implications, considering the tendency of clinicians to continue advocating for life-prolonging treatment, even for patients at the end of life, when implementation of aggressive treatment modalities are likely health-harming, unnecessary, and often futile. The early implementation of palliative care has clinically based potential to improve patient quality of life, bolster care satisfaction, and reduce physical and psychological symptom severity. But perhaps most meaningful is the potential for early palliative care to reduce undue suffering and prepare patients for a dignified death.

The researchers of a recent study sought to examine the timeliness of patient referral to outpatient palliative care before and after the publication of trials demonstrating the benefits of early palliative care concurrent with standard oncology care, such as those conducted by Bakitas, Doyle Lyons, Hegel, Balan, Brokaw, et al. (2009) and Temel et al. (2010) (Hausner et al., 2021). The study compared timing of oncologists' referral, categorized as early (≥ 12 months from referral to death), intermediate (> 6 months to 12 months from referral to death), and late (≤ 6 months from referral to death), between a pre-evidence and a post-evidence cohort of

patients. The researchers found that following the publication of evidence supporting early palliative care, the percentage of late referrals decreased from 68.8% to 44.8%, and the percentage of early referrals increased from 13.4% to 31.1% (Hausner et al., 2021). Further data analysis confirmed that evidence publication significantly increased early referral ($p < 0.0001$), even when adjusted for timing of diagnosis and reason for consultation (Hausner et al., 2021). These findings confirm that the publication of palliative care research has the potential to tangibly change clinical oncology practice, given that oncologists perceive patient benefit and palliative care services are readily available.

One method for disseminating recently published research to shape clinical practice is the formation of clinical practice opinions by well-established and highly regarded professional organizations. The development of the 2012 American Society of Clinical Oncology (ASCO) provisional clinical opinion (PCO) served as a landmark reflection of expert consensus on palliative care utilization in the oncology setting. The 2012 ASCO PCO was foundationally informed by a systematic review conducted by the National Cancer Institute Physicians Data Query, which included findings from Bakitas, Doyle Lyons, Hegel, Balan, Brokaw, et al. (2009) and Temel et al. (2010), and five other RCTs with complementary early palliative care interventions and similar promising results (Smith et al., 2012). The PCO stated:

Substantial evidence demonstrates that palliative care—when combined with standard cancer care or as the main focus of care—leads to better patient and caregiver outcomes. These include improvement in symptoms, quality of life, and patient satisfaction, with reduced caregiver burden. Earlier involvement of palliative care also leads to more appropriate referral to and use of hospice, and reduced use of futile intensive care... Therefore, it is the Panel's expert consensus that combined standard oncology care and

palliative care should be considered early in the course of illness for any patient with metastatic cancer and/or high symptom burden (Smith et al., 2012).

Furthermore, the Panel identified optimization of concurrent palliative care and standard oncology care as an area of necessary continued research (Smith et al., 2012).

The researchers of another c-RCT included in the Haun et al. (2017) review obtained modest data to support the integration of early palliative care into oncology care in the form of outpatient consultation (Zimmerman et al., 2014). 461 eligible patients with either stage III or IV cancer and an estimated survival of 6-24 months, were assigned to receive either immediate consultation and follow-up by a palliative care team, or standard oncology care, in which palliative care was not denied if requested, but usually not offered until completion of the study after four months. The patients in the intervention group received care from a palliative care physician and nurse, including an initial comprehensive assessment of symptoms, psychological distress, social support, and home services. This was followed by routine telephone contact from a palliative care nurse one week after the first consultation and as subsequently needed, along with monthly outpatient care follow-up appointments, and use of a 24 hour on-call telephone service for urgent concerns. The primary outcome identified was patients' self-reported quality of life, measured by the Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being (FACIT-Sp) scale at three months. The researchers additionally collected data measuring symptom severity (Edmonton Symptom Assessment System [ESAS]), satisfaction with care (FAMCARE-P16), and problems with medical interactions (Cancer Rehabilitation Evaluation System Medical Interaction Scale [CARES-MIS]), at baseline, three months, and again at four months. Interestingly, the differences in quality of life scores between the two groups were non-significant at three months ($p = 0.07$) (Zimmerman et al., 2014). However, at four months, the

patients in the early palliative care group reported significantly improved quality of life ($p = 0.006$), higher satisfaction with care ($p < 0.001$), and reduced symptom severity ($p = 0.05$) compared to the standard oncology group (Zimmerman et al., 2014). The difference between reported problems with medical interactions between the two groups remained non-significant ($p = 0.11$) (Zimmerman et al., 2014). The comparatively worse health status of the intervention group noted at baseline may have contributed to a steeper decline in quality of life for the intervention group patients, confounding data collected at the three month point. Nonetheless, the researchers concluded that the early palliative care intervention ultimately improved patients' quality of life, care satisfaction, and marginally reduced symptom burden. Therefore, support for the earlier involvement of palliative care teams in advanced cancer treatment was maintained.

A recently published study offered an opposing perspective on the influence of baseline health status on the efficacy of early integrated palliative care interventions (Rodin et al., 2021). While Zimmerman et al. (2104) suggested that the higher symptom burden of the intervention group may have contributed to a steeper decline in quality of life despite palliative care, Rodin et al. (2021) hypothesized that patients with higher symptom burden would experience greater improvements in quality of life, symptom control, satisfaction with care, and clinician-patient interactions than patients with comparatively lower symptom burden. To evaluate this conjecture, the researchers implemented the same palliative care implementation and applied the same participant criteria as Zimmerman et al. (2014), the primary outcome being quality of life as measured by the FACIT-Sp scale after four months of study. The researchers also assessed quality of life with the Quality of Life at the End of Life (QUAL-E) scale, as well as satisfaction with care (measured by the FAMCARE-P16), and clinician-patient outcomes (measured by CARES-MIS). Unlike Zimmerman et al. (2014), the Rodin et al. (2021) study was nuanced by

the inclusion of an additional variable: symptom severity at baseline (measured by the Edmonton Symptom Assessment System, Symptom Distress Score [ESAS SDS]). Out of the 229 patients with high symptom burden (defined as ESAS SDS > 23), those in the early palliative care group reported significantly improved quality of life ($p = 0.01$; $p = 0.02$), improved satisfaction with care ($p = 0.001$), and improved clinician-patient interactions ($p = 0.04$) (Rodin et al., 2021). Comparatively, for the 232 patients with low symptom burden (defined as ESAS SDS \leq 23), between patients in the early palliative care intervention group and the standard oncologic care control group, there were no statistically significant differences in reported quality of life, satisfaction with care, clinician-patient interactions, or symptom severity (Rodin et al., 2021). Therefore, the researchers concluded that for cancer patients with high symptom burden at baseline, the integration of early palliative care improved quality of life, satisfaction with care, and clinician-patient interactions, indicating that “symptom severity may be an appropriate criterion to trigger early referrals to [specialty] palliative care” (Rodin et al., 2021). Considering that high symptom severity at baseline appears to be an indication for early palliative care, it is interesting to note that in this study, the early palliative care intervention did not significantly influence symptom severity scores after four months, even in patients with high symptom severity (Rodin et al., 2021). It is important to remember that health-related quality of life was identified as the primary outcome of these studies because it is the central focus of palliative care (Rodin et al., 2021; Zimmerman et al., 2014). While measures of symptom severity reflect one important aspect of patients’ physical functioning, measures of quality of life reflect the health of the whole person by considering multiple domains of well being. Whereas the ESAS SDS consists of a ranking system from zero (best) to ten (worst), for nine prevalent symptoms

(pain, fatigue, drowsiness, nausea, anxiety, depression, appetite, dyspnea, and wellbeing), the FACIT-Sp assesses patients' self-reported physical, social and family, emotional, functional, and spiritual quality of life, with a greater range ranking system that allows for increased specificity in scores. The FACIT-Sp is comparatively more encompassing and offers a more holistic measure of health. Thus, early palliative care offers meaningful improvements to overall health for patients with high symptom severity. The findings of Rodin et al. (2021) largely support a financially pragmatic model of early palliative care integration, in which oncologists provide basic palliative care for patients with lower baseline symptom severity and refer patients with complex problems and higher baseline symptom severity to palliative care specialists. While theoretically sound, the clinical feasibility of the specialist approach to complex palliative care warrants additional consideration.

Considerations for Clinical Implementation

Early palliative care can be integrated into standard oncology care by attending oncologists, specialized palliative care providers, or interdisciplinary palliative care teams. The early palliative care intervention implemented by Bakitas, Doyle Lyons, Hegel, Balan, Brokaw, et al. (2009) was led by two APRNs, both nurse educators with expertise in palliative care. The APRNs were guided by an educational manual, *Charting your Course: An Intervention for People and Families Living with Cancer*, centered on the following core modules: problem solving, communication and social support, symptom management, and advance care planning and unfinished business. Additionally, the APRNs received specialized training in the Project ENABLE framework, and participated in bi-weekly team meetings with the study researchers to review complicated cases. The APRNs conducted an initial, assessment phone call with each patient enrolled in the intervention group, followed by four weekly follow-up calls, each

focusing on one of the core modules, and then monthly follow-up calls until conclusion of the study or patient death. On each call, the patients were asked to rate their distress levels on a zero to ten scale, offering the APRN an opportunity to identify distress and offer problem-solving and coping strategies, as well as triage medical complaints and organize care services as appropriate. Patients in the intervention group were also invited to shared medical appointments with other patients, led by a palliative care physician and nurse practitioner. These appointments were meant to provide patients and their caregivers with an opportunity to openly discuss their medical problems and related issues (including insurance coverage, barriers to care, social services, and rehabilitation services) and learn from the experiences of patients in similar situations. Finally, patients in both the intervention and control group were allowed to use all oncology and medical services available, including a consultative interdisciplinary palliative team comprised of physicians, nurse practitioners, a social worker, a chaplain, a volunteer coordinator and volunteers, and administrative staff (Bakitas, Doyle Lyons, Hegel, Balan, Barnett, et al., 2009). Considering the improvements in quality of life and mood reported by patients who received the early palliative care intervention in this study (Bakitas, Doyle Lyons, Hegel, Balan, Brokaw, et al., 2009), this model of palliative care provision (as well as this model of provider specialty training and interdisciplinary support) carries potential for additional clinical implementation.

The review of evidence presented by Bruera & Hui (2010) includes discussion of three potential models of palliative care for use by oncologists, who are primarily responsible for determining the need for, and timing of referral to palliative care. In the “Solo Practice Model,” the oncologist provides cancer assessment and treatment as well as palliative care. This model may be advantageous in small communities or rural areas, in which access to palliative care

resources is limited. However, disadvantages of this model include time constraints, limited palliative care training, and provider burnout. In the “Congress Practice Model,” the oncologist provides cancer assessment and treatment, and refers the patient to multiple specialists for the multiple aspects of palliative care (for example, a pain consult for pain, a pulmonary consult for dyspnea, and a psychiatry consult for depression). This model is an attempt at comprehensive care, yet poses many disadvantages, the most glaring being care fragmentation. The most promising alternative is the “Integrated Care Model,” in which the oncologist provides cancer assessment and treatment, and an interdisciplinary supportive care team addresses the majority of physical and psychosocial concerns, simplifying appointments and improving cost efficiency (Bruera & Hui, 2010). The oncologist and care team closely collaborate, and include consultation with other specialties as necessary, to provide comprehensive, integrated early palliative care concurrent with standard oncology care.

The “Integrated Care Model” presented by Bruera & Hui (2010) most closely reflects the 2017 ASCO expert consensus. The current PCO, founded on a systematic review of recent palliative care literature, reads:

Patients with advanced cancer, whether patient or outpatient, should receive dedicated palliative care services, early in the disease course, concurrent with active treatment.

Referring patients to interdisciplinary palliative care teams is optimal, and services may complement existing programs. Providers may refer caregivers of patients with early or advanced cancer to palliative care services (Ferrell et al., 2017).

The unifying element among successful interventions identified by the panel was the utilization of interdisciplinary palliative care teams that sought to improve patient quality of life in physical, psychological, spiritual, and social domains. For patients with high symptom burden and/or

unmet needs, the panel suggests that outpatient care clinics employ palliative care clinicians to provide specialized care (Ferrell et al., 2017), affirming the findings of Rodin et al. (2021).

Nursing Implications

Plentiful evidence confirms that early, integrated, palliative care improves quality of life measures for patients with advanced cancers, and current clinical guidelines recommend utilization of interdisciplinary palliative care models in oncology practice. But what is the role of the oncology nurse in introducing and providing integrated care? Mohammed et al. (2020) conducted interviews of nurses and APRNs to examine the psychological processes through which ambulatory cancer care nurses engage in facilitating palliative care early in the disease course. Study participants were asked open-ended questions about nurses' perceptions of early palliative care, their experience introducing palliative care to patients, and their sense of the nurse's role in the palliative care team. Coding and analysis of the responses allowed the researchers to identify four core elements of nurses' involvement in "brokering" palliative care, or in other words, gently educating patients on the benefits of palliative care while being mindful of misconceptions and assuring patients that referral could be considered at the patient's own pace. To effectively advocate for early palliative care referral, nurses are tasked with "opening the door," by assessing the willingness of their patients to hear about palliative care, and then presenting information about available services and allowing patients time for reflection before moving forward. Nurses are in positions to "cultivate trust" through utilization of relational skills with both patients and palliative care providers, to mediate referral contemplation on both sides. Nurses are also tasked with "tackling misconceptions" about palliative care (such as the assumption that palliative care is synonymous with end of life or hospice care) to reduce patient fear. Finally, nurses must "advocate with oncologists" to recommend palliative care integration

based on holistic nursing assessment. Researchers note that the nurses “had to advance palliative care in a measured and subtle way... assessing and retreating when necessary, since they often lacked the clinical authority to formally direct treatment” (Mohammed et al., 2020). However, even without the clinical authority to independently initiate palliative care, Mohammed et al. (2020) affirms that nurses are instrumental in advocating for the implementation of early, integrated palliative care, and recommends fundamental palliative care training for all nurses to increase nurse-initiated early referral to palliative care services. A recently completed qualitative survey also identified a need for improved clinical education regarding palliative care practices and benefits of early implementation, specifically for oncology APRNs, who have the clinical authority to take the lead in implementing such care for their patients (Mason et al., 2021). Furthermore, Mason et al. (2021) recommends that all providers should receive training on palliative care principles such that they feel comfortable initiating discussions regarding prognosis and goals of care for their patients. All healthcare providers have a responsibility to consider the implications of cancer prognosis and potentially aggressive, life-sustaining treatment on patient quality of life, and appropriately advocate for early, integrated palliative care to alleviate suffering and honor human dignity.

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Appendix

A. Symposium Speech

I'll be opening my project presentation with a case study. In medicine, it is common practice for physicians to gather for morbidity and mortality conferences, which involve analysis of adverse outcomes in patient care, especially those that expose systems level issues in healthcare. It is my hope that by opening with this case study, I'll encourage all of you to think critically about tangible ways by which we can improve standard clinical practice to improve quality of care for patients with advanced cancer.

Patient X was a 48 year old female, followed by oncologists for recurrent stage four B cervical cancer, with recent metastasis to the surrounding lymph nodes, liver, and lungs. Patient X had been admitted 8 times over the course of 14 months, for cancer treatment as well as management of complications of treatment, including stage 3B kidney failure. On August 9th, 2021, Patient X was admitted for her fourth round of chemotherapy, which at this point, was a combination of three experimental drugs. On August 10th, an MRI confirmed her worst fear: the cancer had metastasized to her brain. The oncology team discussed the prognosis with patient X and her family, and recommended an immediate transition to inpatient hospice care. Instead, patient X convinced herself and her family that she was capable of recovery, and despite her family's pleas, left the hospital the next morning, intending to receive experimental immunotherapy from an outside oncologist. Unfortunately, patient X never made it to her consult appointment. Less than 10 hours after leaving the hospital, her family rushed her back to the emergency department with altered mental status: patient X was severely disoriented, her speech

was incomprehensible, and she could no longer recognize her family. Patient X died in the hospital four days later, on August 16th at 11:14 am. She never accepted hospice care.

When I first considered pursuing a career in nursing, I conceptualized healthcare as the intersection between scientifically grounded medical advancements and profoundly personal moments of human connection cultivated to promote holistic healing. Even at a young age, I knew the capacity of nurses to provide meaningful care at what may be the most important time in a patient's life. What I failed to consider was the potential for devastating strain between purely scientific medicine seeking to prolong life at any cost, and providing ethical care that considers what makes one human and upholds dignity. Working on an oncology floor as a nursing student, I quickly came to learn that this strain is especially pronounced in critically ill patients, and even more poignant in terminally ill patients approaching the end of life.

I had the privilege of caring for patient X over the course of multiple admissions, and I watched her gradually deteriorate with each round of treatment. I understood that the chemotherapy she received was intended to prevent cancer growth and metastasis to prolong her life. I also understood that the chemotherapy directly contributed to her extreme fatigue, nausea and vomiting, malnourishment, anemia, recurrent infections, and kidney failure. On days on which she rated her pain as 10/10 despite continuous infusions of pain medications, or felt too nauseous to keep down anything other than ice chips, or felt too fatigued to stand up without me fully supporting her small frame, I felt something that I hadn't before felt while caring for a patient: guilt. While I understood the scientific rationale behind every medical and nursing intervention we provided patient X, I also felt that treatment was doing more harm than good. I wondered, how do we, as healthcare professionals, support and provide life-sustaining medical

interventions, when such aggressive treatments are often accompanied by devastatingly detrimental symptoms and decreased patient quality of life?

Guided by this overarching question, my research interest reflected my commitment to uncovering tangible ways by which healthcare professionals can engage in research and utilize evidence-based knowledge to improve care quality and ease human suffering. This is important to acknowledge, in light of the philosophy presented by Professor John Frow, in his work *On Interpretative Conflict*. Frow writes, and I quote, “knowledge is never simply a reflex function of institutions, and it is never simply detachable from social interest. It is always at once a way of representing the world and a form of social organization that carries our position in and toward the world,” end quote. If knowledge carries our position in and toward the world, I hope that presenting my research on palliative care carries my position as one of kindness and gentleness as I seek to meaningfully care for others.

Palliative care is both a philosophy of care and a highly structured system for care delivery that aims to improve the quality of life of any patient with advanced, serious illness, including cancers. Current clinical guidelines define palliative care as “an interdisciplinary care delivery system designed to anticipate, prevent, and manage physical, psychological, social, and spiritual suffering to optimize quality of life for patients, their families and caregivers ... [This is done through] expert assessment and management of pain and other symptoms, assessment and support of caregiver needs, and coordination of care.” Unlike hospice care, which is reserved for patients with a life expectancy of 6 months or less, palliative care can be given to any patient, with any serious illness, regardless of prognosis. Furthermore, palliative care can be utilized in conjunction with curative treatment that seeks to prolong life, such as chemotherapy, radiation, and surgical resection of tumors.

Unfortunately, the prevalent misconception that palliative care is synonymous with hospice care contributes to an underuse of palliative care principles and specialty referral. Data from the World Health Organization indicates that only an estimated 14% of patients who need palliative care actually receive it. My project aims to inform oncology nursing practice through the analysis of literature and clinical guidelines supporting the early integration of palliative care with standard curative oncology treatment for patients with advanced cancer. I remain hopeful that through the dissemination of clinical research, the clarification of clinician's roles in palliative care delivery models, and the expansion of specialty training in medical and nursing schools, we may revolutionize the standard approach to complex cancer care.

My literature review was largely guided by a Cochrane Systematic Review published in 2017. The authors of this review compared the findings of seven randomized control trials in which cancer patients were offered either palliative care concurrent with standard oncology care during or shortly after the time of diagnosis, or standard oncology care. The reviewers focused on the primary outcomes of health-related quality of life, and also measured symptom intensity and survival rates for the two intervention groups. Many of the early palliative care interventions studied were led by palliative care advanced practice nurses, who initially met with each patient and their family to discuss the prognosis, consider treatment options, and establish goals of care. This was preceded by regularly scheduled follow-up care, in which the advanced practice nurses utilized assessment tools to identify, prevent, and alleviate physical and psychological symptoms. The patients also received coaching on problem-solving, family and healthcare team communication strategies, advance care planning, symptom management, crisis prevention, and referral to hospice services. The advanced practice nurses developed therapeutic bonds with the patients and their families, and acted as the primary palliative care providers, while consulting

with oncology physicians and specialists in respiratory therapy, and physical therapy, psychiatry, and social work. The authors of the study hypothesized that patients diagnosed with advanced, life-limiting cancer (often with a prognosis of approximately 1 year) would grow into informed, active participants in their care, and thereby experience better outcomes. Synthesis of data from a collective sample size of 1,028 participants indicated that compared to the standard oncology care patients, the patients who received the early palliative care reported significantly higher quality of life and lower symptom intensity for both physical and psychological symptoms.

The data from one specific trial in this review found that the patients in the early palliative care intervention received significantly less aggressive end of life care, meaning less chemotherapy and longer hospice care, than the patients in standard oncology care. Interestingly, early palliative care patients still survived an average of 2.7 months longer than the standard oncology care patients. While survival rates were not the primary outcome of this study nor my research, this finding has relevant implications, considering the tendency of providers to continue advocating for aggressive life-prolonging treatment, even for patients at the end of life, when this treatment is health-harming and often futile. Early integrated palliative care offers opportunities for oncology patients and caregivers to deeply consider the implications of prognosis and actively participate in care decisions. This provides an opportunity for healthcare providers to align prescribed treatment plans with patient goals of care, reduce undue suffering, and perhaps most importantly, prepare patients for a dignified death.

While there are a few clinical models by which early palliative care can be integrated into standard oncology care, it's notable that the unifying element among successful interventions was the utilization of interdisciplinary palliative care teams. The American Society of Clinical Oncology supports implementation of the "Integrated Care Model," in which the attending

oncologist provides cancer treatment, and closely collaborates with an interdisciplinary palliative care team (consisting of physicians, nurse practitioners, respiratory therapists, nutritionists, social workers, counselors, and chaplains) to provide comprehensive, integrated support.

Considering this research and current clinical guidelines, as well as the importance of an interdisciplinary approach, the question arises: what is the role of the oncology nurse in proactively introducing and providing integrated palliative care? The authors of one study sought to answer exactly that, by conducting a survey of nurses who successfully introduced early palliative care in an ambulatory cancer care clinic. The nurses' described their integral involvement in "brokering" palliative care, or in other words, gently educating patients on the benefits of palliative care while being mindful of misconceptions and assuring patients that referral could be considered at the patient's own pace. The researchers identified four core elements: first, nurses are tasked with "opening the door," by assessing the willingness of their patients to hear about palliative care, and then presenting information about available services and allowing patients time for reflection before moving forward. Nurses are in positions to "cultivate trust" through utilization of relational skills with both patients and palliative care providers, to mediate referral contemplation on both sides. Nurses are also tasked with "tackling misconceptions" about palliative care (such as the assumption that palliative care is synonymous with end of life or hospice care) to reduce patient fear. Finally, nurses must "advocate with oncologists" to recommend palliative care integration based on holistic nursing assessment.

A recently completed qualitative survey also identified a need for improved clinical education regarding palliative care practices and benefits of early implementation, specifically for advanced practice oncology nurses, who have the clinical authority to take the lead in implementing such care for their patients. Furthermore, all providers should receive training on

palliative care principles such that they feel comfortable initiating discussions regarding prognosis and goals of care for their patients. Medical practice is founded on a dedication to healing. All healthcare professionals have a responsibility to consider the implications of treatment, and advocate for holistically healing clinical practices to honor human dignity at every stage of illness, including and especially at the end of life.

I think of patient X everytime I offer one of my patients a warm blanket. At the end of her life, this was the only intervention that made her smile, regardless of her pain, nausea, or depressed mood. It was the one thing I could do to bring her just a little bit of comfort. Palliative care is foundationally, a philosophy of care. For me, this philosophy is most profoundly reflected in these seemingly little moments. The gentle presence of someone who cares. A hand to hold. A moment of silence to share in the heaviness. A warm blanket.

I think I'll always look back on my interactions with patient X and wonder how her life might have ended differently had palliative care been integrated into her treatment plan. However I'm resolved to carry forward both my reflections on patient X, as well as the palliative care research she inspired. I hope that my future nursing care will exemplify this dedication to care for the whole person. And I hope that sharing this disciplinary knowledge will inspire all of you to intentionally seek out the little moments in which you can care for others. Thank you.

B. Symposium Visual

Early Integration of Palliative Care with Curative Oncology Treatment for Patients with Advanced Cancer: Implications for Clinical Nursing Practice

Rhea Rughani & Advisor Professor Desiree Hoffman

Patient X: 48 year old female
HPI: Stage IVB cervical cancer, with systemic metastasis
Standard Tx: Experimental chemotherapy

Clinical Implementation: Integrated Care Model

Nursing Implications: Open the door, Cultivate trust,
Tackle misconceptions, Advocate with oncologists

