

Improving patient referrals to specialty palliative care:
A quality improvement project in a Portland oncology clinic

Priya Keane

Oregon Health & Science University

Abstract

There are numerous benefits of early inclusion of palliative care (PC) in patients with advanced cancer. Though many organizations support the integration of early PC alongside standard oncology care, a gap exists between the evidence based guidelines and clinical practice as patients with advanced cancer are not routinely referred to PC early after diagnosis. This was true at the OHSU outpatient community oncology clinics where the average referral rates of patients with newly diagnosed metastatic lung cancer failed to meet their target. This quality improvement project sought to improve patient referrals to PC through multiple interventions including informational interviews, a staff survey, and an educational video. The interviews highlighted underutilization of the nursing role in the referral process. This informed a survey which assessed nursing knowledge about PC and barriers to referral. Survey results indicated that nurses had a basic knowledge of PC and its benefits but lacked in-depth education and felt they needed more information to comfortably refer patients to PC. It also highlighted unfamiliarity with clinic policy allowing nurses to independently refer patients to PC. These findings led to a video that reinforced nursing knowledge about PC, highlighted effective communication strategies to dispel myths about PC with patients and their families, discussed how to place a referral to PC, and provided tools for empathic communication. Overall this project helped improve the PC referral process at the OHSU outpatient oncology clinics by identifying barriers to PC referral and staff knowledge gaps and sought to remedy them with staff education.

Improving patient referrals to specialty palliative care:

A quality improvement project in a Portland oncology clinic

Introduction

Palliative care (PC) is a multidisciplinary medical specialty that focuses on quality of life for patients with life-threatening illness as well as their families (Kelley & Morrison, 2015; Saga, Enokido, Iwata & Ogawa, 2018). PC is found in a variety of settings, including hospitals, clinics, cancer centers, nursing homes, and home care programs (Kelley & Morrison, 2015). Though multiple definitions exist, one of the commonly used definitions is that of the National Consensus Project for Quality Palliative Care (NCPQPC), which states,

Palliative care means patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information and choice (NCPQPC, 2012, p. 9).

One of the most studied disease processes in relation to PC is cancer. Once very limited, treatment for cancer has expanded rapidly in the last few decades (Greer, Jackson, Meier, & Temel, 2013; Hui, Hannon, Zimmermann, & Bruera, 2018). Traditional models of care introduced PC late in the illness trajectory when life-prolonging or curative treatments were no longer available, which showed some benefit on symptom reduction, family satisfaction, and quality of life (Kelley & Morrison, 2015; Parikh, Kirch, Smith & Temel, 2013). Given the need for urgent advanced care planning and symptom management in advanced cancer, studies began to focus on the use of PC in conjunction with curative treatment, an idea known as early PC (Greer, Jackson, Meier & Temel, 2013; Parikh et al., 2013). For the purpose of this project,

advanced cancer will follow the definition used by the American Society of Clinical Oncology (ASCO), which includes “distant metastases, late-stage disease, cancer that is life limiting, and/or a prognosis of six to 24 months” (Ferrell et al., 2017, p. 96).

A landmark study by Temel et al. (2010) showed improved quality of life and decreased depressive symptoms in patients with metastatic non-small cell lung cancer (NSCLC) who were connected with a PC team within three weeks of diagnosis. Subsequent research has focused on timing of integration of early PC in advanced cancer. Beneficial outcomes from the use of early PC in these studies led ASCO to update their guidelines in 2016 to recommend inpatient and outpatient PC referral within eight weeks of diagnosis of advanced or metastatic cancer in conjunction with active treatment for patients with advanced cancer (Ferrell et al., 2017).

Problem Description

Though many organizations now support the integration of early PC with standard oncology care, a gap still exists between the evidence based guidelines and actual clinical practice as patients with advanced or metastatic cancer are not routinely referred to PC within eight weeks of diagnosis (Hui et al., 2016; Institute of Medicine, 2014). A recent retrospective study examined 23,154 patients with advanced lung cancer (stage IIIB and stage IV) receiving care through the Veterans Affairs health system and found that just 57% received PC at any point prior to death (Sullivan et al., 2019).

Available Knowledge

One of the main reasons for this gap is a lack of understanding of PC, both on the part of patients and providers. Many patients confuse PC with hospice, or end of life care, which serves as a barrier to referral. Other barriers include referral patterns, unfavorable attitudes toward PC, and a workforce shortage of PC specialists.

Barriers to palliative care referral.

Patient knowledge of palliative care. There is confusion amongst patients that PC is synonymous with end of life care, or hospice. This is an unfortunate misrepresentation of what PC has to offer. In a 2016 study of 800 adults in the state of New York, only 26% of respondents could accurately define PC, a finding consistent with previous nationwide surveys (Lane, Ramadurai & Simonetti, 2019; Shalev, Phongtankuel, Kozlov, Shen, Adelman & Reid, 2017). Interestingly, once educated about PC, nine out of 10 respondents felt it would be helpful for sick patients and their families (Lane, Ramadurai & Simonetti, 2019).

Another study examined perceptions about PC among patients with advanced cancer enrolled in a randomized controlled trial that sought to determine the benefits of early PC. 48 patients (26 intervention, 22 control) and 23 caregivers (14 intervention, 9 control) completed interviews after participating in the trial (Zimmermann et al., 2016). Many patients in both groups described their initial opinions of PC as related to death, comfort care, and hopelessness. Despite appreciating the benefit of early PC, the intervention group still felt the term carried stigma and thought communication about the definition of PC could be improved (Zimmermann et al., 2016).

Provider attitudes. Confusion regarding use of PC is not just limited to patients. Many providers have similar misperceptions that PC is synonymous with end of life care (Buckley de Meritens et al., 2017; Hui et al., 2018). Buckley de Meritens et al. (2017) sought to examine the beliefs of gynecologic oncologists regarding PC. 709 members of the Society of Gynecologic Oncology were sent an electronic survey and 145 (20%) completed the survey, a majority of whom were attending physicians working at university hospitals throughout the United States.

While 97% of respondents believed that PC was a beneficial adjunct to oncology care, only 17% felt a PC consult was appropriate at diagnosis. 42% felt that a PC consult was appropriate when a patient had a prognosis of six months or less, and a majority felt the greatest benefit from PC consult came when the patient was transitioning to end of life care (Buckley de Meritens et al., 2017). Respondents cited their main barrier to PC referral was fear of patient and family feeling of abandonment (Buckley de Meritens et al., 2017, p. e707). This feeling is one that has been described in previous studies surveying other types of oncologists as well. The low response rate introduces the possibility of selection bias but overall the demographics of responding physicians were similar to overall member demographics. Buckley de Meritens et al. (2017) also note that the response rate was not unusual for a physician survey and similarly designed surveys have been well established as an effective method for studying physician beliefs.

Schenker et al. (2014) sought to better understand oncologist attitudes that influence referrals to outpatient PC by conducting semi structured interviews with medical oncologists at three different academic cancer centers across the United States. The cancer centers were chosen based on proximity to well established outpatient palliative care clinics. Qualitative data were analyzed using constant comparative methods and reliability was assessed through use of a second independent investigator (Schenker et al., 2014).

Of the 94 oncologists contacted, 74 participated in interviews (Schenker et al., 2014). The average length of practice was 17 years. Schenker et al. (2014) determined three main barriers to PC referral including: the belief that PC is philosophically incompatible with traditional cancer treatment, the feeling that providing PC is the responsibility of the oncologist, and lack of familiarity with PC availability. Schenker et al. (2014) note that the view that PC was not

compatible with curative treatment was voiced by a minority of participants across all centers and expressed most often by the longest practicing oncologists. Other participants felt PC was complementary to traditional treatment and were most likely to refer to PC for assistance with pain symptoms (Schenker et al., 2014).

Strengths of this study included use of multiple sites, high response rate, and use of a second investigator to strengthen validity. Given the very focused study population, generalizability is limited beyond medical oncologists at large academic cancer centers. Buckley de Meritens et al. (2017) and Schenker et al. (2014) demonstrate that further work needs to be done to improve understanding of specialty PC and its benefits with certain oncology patients.

Referral patterns. Hui et al. (2018) examined patterns of outpatient PC referral among thoracic medical oncologists, a field where those with advanced cancer have both a high symptom burden and poor prognosis. They performed chart reviews on 1,642 patients who died of advanced thoracic malignancy. 27% had an outpatient PC referral prior to death and 29% had an inpatient PC referral prior to death (Hui et al., 2018). Based on the data, thoracic oncologists were categorized as high referring oncologists (median 37% referral rate) or low referring (median 24% referral rate), which were determined based on dividing the data into two groups at the median. Differences between the two groups showed high referring oncologists were more likely to be younger and refer patients earlier in their disease course (Hui et al., 2018). One potential for low overall referral rates is that the thoracic oncologists felt they were providing adequate symptom management, or primary PC.

In another study examining gynecologic oncology patients who met the ASCO criteria for PC referral only 53% had PC consults prior to death (Buckley de Meritens et al., 2017). In a separate study at a comprehensive cancer care center, only 45% of patients had PC consults by

their death with the median time from PC consult to death being 6 to 7 days (Buckley de Meritens et al., 2017).

These referral patterns support the idea that oncology practices have yet to incorporate the guidelines for early PC referrals for their patients with advanced cancer. It is likely that these late referral patterns reinforce patient perceptions that PC is synonymous with end of life care and lead to the sense of abandonment patients describe with PC referral.

Workforce shortage. PC is a relatively new specialty in the field of medicine as specialty certifications through the American Board of Internal Medicine began in 2008 (LeBlanc, Sederstrom, Spence, & von Roenn, 2017). Because of this, there are not enough specialty PC providers for all the patients currently meeting the guidelines for palliative care referral. Lupu (2010) sought to determine the anticipated workforce shortage in Hospice and Palliative Care physicians and found the estimated gap to be anywhere from 6,000 to 18,000 individual physicians (variation due to individual FTE). One way to minimize this shortage is through the use of both advanced practice and registered nurses (RNs), though little research exists regarding the hospice and PC nursing workforce shortage (Palliative and Hospice Nursing Professional Issues Panel, 2017).

Given these likely shortages, many have suggested screening tools to distinguish between primary and secondary (or specialty) PC. Primary PC is basic symptom management and advanced care planning that is provided by the oncologist or primary care provider whereas secondary PC is performed by specialty PC providers and addresses more complex patient needs (Hui, Hannon, Zimmermann, & Bruera, 2019). One difficulty with this model is that PC education is grossly lacking in oncology training, with only 20-25% of medical oncology fellowship programs including PC rotations (Hui et al., 2019). Interestingly, exposure to PC

during fellowship is associated with increased referral rates to specialty PC (Finlay, Rabow, & Buss, 2018). In general, the data supporting early PC suggests that multidisciplinary teams including physicians, advanced practice providers, RNs, social workers, and chaplains may have the greatest benefit for patients (Hui, 2019).

Rationale

The model that informed this quality improvement project was Rosswurm and Larabee's model for change (White, 2015). Rosswurm and Larabee (1999) detailed a six step model including an assessment of need for change based on a comparison of internal and external data, determination of potential interventions and outcomes, review of evidence, design and implementation of practice change, evaluation of practice change, and sustainability of practice change through diffusion strategies. Though Rosswurm and Larabee designed their model for acute care, they felt it was flexible enough to also apply to outpatient settings (White, 2015).

The project fit well within Rosswurm and Larabee's model for change as there was existing internal data that supported the need for a change in practice as well as stakeholders within the determined organization who were ready to move to evidence based practice. The model also recommends change based on a variety of data including clinical expertise and contextual evidence, both of which informed the project (Rosswurm & Larabee, 1999).

Specific Aims

The purpose of this quality improvement project was to improve PC referrals for patients with advanced or metastatic cancer and improve staff knowledge of PC at the Oregon Health & Science University (OHSU) Knight Cancer Institute outpatient clinic in east Portland. Aims

included assessment of provider and RN attitudes as well as clinic barriers to PC referral, creation of a standardized PC referral algorithm, and improved staff knowledge regarding PC.

Methods

Context

OHSU has five community oncology clinics in addition to offices on its main campus. These community clinics seek to provide accessible quality care to patients throughout the Portland metro area. The east Portland clinic serves many low income patients and has the lowest rates of PC appointments of all the clinics that have PC coverage one day each week (S. Lowry, personal communication, November 14, 2019). The east Portland clinic is staffed by two oncologists, two nurse practitioners, including one PC nurse practitioner, triage and infusion RNs, an RN navigator (a relatively new role that is similar to a case manager), and various support staff (M. Davis, personal communication, November 4, 2019).

The community oncology clinics track various quality metrics determined by the Centers for Medicare and Medicaid Services (CMS). These metrics, such as percentage of patients who received chemotherapy in the last 14 days of life, the rate and duration of hospice enrollment, and PC referrals for patients with stage four lung cancer within 12 weeks of diagnosis showed there was a need for earlier referral to supportive care at the east Portland clinic. The clinic tracked PC referrals for patients with stage four lung cancer since the fourth quarter of fiscal year 2018 with the ultimate goal of greater than 90% referral rates. Since they began tracking the data the average quarterly referral rates had increased but still not met their target. The average referral rate over the five tracked quarters was 66.6%.

Overall PC referrals are also tracked by the Administrative Coordinator for Survivorship and PC (A. Lipari, personal communication, November 1, 2019). As of September 2019, 367

patients received PC referrals and 318 were seen by PC in 2019 (A. Lipari, personal communication, November 1, 2019). This data also showed the opportunity for improved referral pathways as it identified 58 patients with metastatic cancer who were not referred to PC (A. Lipari, personal communication, November 1, 2019). One of the changes made to improve these referrals was the allowance of RNs to refer patients to PC, however actual referrals from RNs remained low (S. Lowry, personal communication, August 26, 2019).

Interventions

This project used multifaceted interventions to achieve its goal of improved PC referrals for patients with advanced or metastatic cancer. These included:

- Pilot interviews that determined the intervention population
- A pre-implementation survey created through REDCap (Research Electronic Data Capture) that assessed RN PC knowledge and attitudes, as well as barriers to PC referral
- Creation of a standardized PC referral algorithm for providers and RNs to use that would include a standardized process for scheduling initial PC appointments. The referral algorithm would be based on existing evidence including but not limited to: National Comprehensive Cancer Network and ASCO PC referral guidelines and international consensus data on referral criteria. The algorithm would also be informed by interviews with the clinic PC providers, RN navigators, and other involved staff.
- Clinic-wide education regarding use of referral algorithm, the referral process, and perceived barriers to referral.

- Staff education regarding PC and its benefits in the form of in-person teaching sessions

Study of the Interventions

The impact of the interventions was approached multiple ways. First, referral rates of patients with advanced or metastatic cancer were examined before the implementation of the referral algorithm. Next, targeted education was created based on results from the pre-implementation survey and pre and post-testing were planned to determine the efficacy of this education. Finally, post-intervention informative interviews were planned to determine future needs. Given time constraints, a post intervention evaluation survey was recommended for a future project.

The bundled intervention approach was used to increase the likelihood that improved PC referrals were because of the quality improvement project and not due to chance. The multimodal approach helped increase staff awareness of the quality improvement project.

Measures

Qualitative data collection, in the form of pilot interviews and surveys, was performed using REDCap to collect and manage the data. Pilot interviews were measured through inductive content analysis to determine prominent the themes that arose. These themes were cross referenced with existing literature to best inform the referral algorithm and staff education.

Analysis

Surveys were analyzed using simple statistics as well as inductive content analysis to determine prominent themes, which were mapped using frequency histograms.

Ethical Considerations

It was possible that some patients who would benefit from PC would fall outside of the referral algorithm. Given that it would be unethical to withhold the benefit of PC because of a study, it was imperative to impress upon clinic staff that referrals should be made to anyone requesting PC. It was also necessary to recognize the sensitive nature of topics surrounding death and dying and to approach interviews, surveys, and education with respect for different values and belief systems.

Results

Pilot interviews.

The initial pilot interviews with various clinic staff ultimately determined the shape of the quality improvement project. Discussions took place with the two clinic PC Nurse Practitioners, RN Navigators, clinic social worker, RN manager, and various infusion and triage RNs. Through these conversations and research regarding available PC referral algorithms, it was determined that use of a referral algorithm was exceedingly time-consuming for staff and unnecessary at the present time. However, two prominent themes arose from these interviews.

The first was the underutilization of the nursing role in the referral process. Infusion RNs regularly assess symptoms as a part of their standard workflow and triage RNs often call patients when they miss appointments to determine why. This firsthand knowledge meant RNs are uniquely positioned to make early referrals to palliative care, especially for things like poorly controlled symptoms or rapidly declining function. Unfortunately, it also became clear that though RNs had the independent ability to refer, many did not. The pilot interviews showed that some RNs didn't feel comfortable referring without provider permission and some simply didn't know it was within their scope of practice.

The second theme was the difficulty of getting patients to accept PC appointments and to show up for them once they were scheduled. One of the difficulties around getting initial PC visits scheduled was getting patient buy-in. Many interviewees felt patients either didn't want to have to come in for yet another appointment or didn't understand how PC might be beneficial for them. It was also difficult to ensure patients attended their PC appointments. Some patient felt too ill to leave the house and would cancel or simply not show up for their appointment at all. There were issues with scheduling PC visits on the same day as a visit with the oncology NP, which meant patients had to come in to the clinic on a separate day for their PC appointment. At the time there were minimal telehealth or phone visits available due to issues with insurance reimbursement, though this has changed recently due to concerns about the rapid spread of coronavirus.

Though it was outside of the scope of this project to try and change insurance reimbursement practices or the way visits were conducted, it was clear that there was room to improve nursing referrals to PC through better understanding perceived barriers and educating clinic RNs about how to overcome obstacles to referral. Because of this, the pre-implementation survey was adjusted to solely target clinic RNs (as opposed to RNs and providers). In an effort to better understand nursing referral behaviors and knowledge throughout the clinics, the survey was sent to all RNs (infusion, triage, RN Navigators, RN educator, and RN manager) across the five clinics, 61 people in total.

Survey results.

Thirty of the 61 recipients returned the survey for a completion rate of 49%. A majority of RNs who completed the survey were infusion RNs and over three-quarters had at least a bachelor's degree. Over 60% have worked in oncology for more than five years and only three

respondents had worked as RNs for less than five years. Other sample characteristics from the survey are listed in Appendix A.

Though only 23.3% of respondents had previously received specialized PC education, almost universally, clinic RNs reported a basic understanding of PC and recognized that it is a multidisciplinary specialty that is not just reserved for end-of-life or those without curative treatment options and important to incorporate early in patients with advanced cancer. All agreed that one of the benefits of PC was enhanced quality of life for patients and their families and many felt that PC provided patients with expert pain and symptom management. Full PC knowledge results are listed in Appendix B. Despite these sentiments, over 30% of respondents felt that patients and their families are unwilling or unready to utilize PC services.

Fifty percent of RNs identified that they had the ability to independently refer patients with metastatic cancer to PC and 46.6% stated they could refer any oncology patient to PC without provider approval. Clinic policy allows RNs to independently refer any oncology patient to PC if they feel a referral is warranted but many RNs noted discomfort with referring patients to PC without first obtaining permission from the patient's oncologist. Only 36.7% of respondents noted they felt comfortable referring patients without provider permission.

In regards to referral patterns, 33.3% responded that they never refer patients to PC, and 46.6% stated they rarely refer patients. 36.7% stated that they both consider and refer patients to PC. RNs were more likely to discuss PC with patients than place a referral. 83.3% noted they discuss PC with patients with poorly controlled symptoms and 70% were likely to consider PC referral even if just one symptom was poorly controlled. Over 70% of RNs considered referral for poorly controlled pain, depression, anxiety, appetite, or poor overall well-being. Just over

half the respondents considered PC referral for patients or family members asking questions about end of life. Full referral results are listed in Appendix C.

RNs had the opportunity to discuss their feelings about barriers to PC referral and how they discuss PC with patients in free text answers at the end of the survey. These answers were reviewed for pertinent themes which are mapped in Appendix D. The main perceived barriers to referral were RNs believing they needed provider permission to make a referral and a feeling that more education about PC was needed in order for RNs to feel comfortable making referrals independently. RNs indicated that more than anything else, they present PC as an option for symptom and stress relief for patients and their families. Many also discuss that it may lead to improved quality of life.

RN Education.

Results from the survey were used to create targeted education for clinic RNs. Initially, this was planned as in-person, one-on-one and small group education taught specifically at the east Portland clinic. Unfortunately, due to the 2020 coronavirus pandemic, limited personal protective equipment and required social distancing, in-person education was not an option. This led to the creation of an educational video that reinforced nursing knowledge about PC, highlighted effective communication strategies to dispel myths about PC with patients and their families, discussed how to place a referral to PC, and provided tools for empathic communication.

Along with presenting basic information about PC the video described some of the benefits seen from incorporating PC early in the treatment of patients with advanced and metastatic cancer including reduced symptom burden and improved quality of life. It was also emphasized that PC is not synonymous with end of life care or hospice.

The RN education presented specific strategies for discussing PC with patients and their families including the road trip metaphor, which likens PC to the preparation that helps a driver arrive at their destination safely and comfortably (Courteau, Chaput, Musgrave, & Khadoury, 2018). The video also discussed RNs ability to independently refer any oncology patient to PC if they felt a referral was appropriate and listed a variety of things that might help trigger an RN to consider referral to PC. Along with dispelling the myth that provider approval was needed for referral, the video described ways to determine if the patient had already seen PC and the exact steps in the referral process including screen shots from the electronic medical record to help train RNs how to make a PC referral. These steps were reinforced in a separate reference document that was provided to RNs along with the video. This document included reasons to consider referral as well as the steps for inputting the referral itself.

Finally, the video described two empathic conversation tools for RNs to use with patients. These included the NURSES mnemonic which is part of the Vital Talk curriculum and is used to respond to emotion with empathy, as well as the three W's, which seeks to help align the RN with the patient's wishes while also allowing them to express their fears back to the patient (Vital Talk, 2019).

Unfortunately staff were inundated with information during the pandemic as many policies and procedures were changing day to day. Because of this, the decision was made to end this quality improvement project after sharing the PC education video for RNs and leave the post-education survey and post-intervention evaluative interviews for a future project.

Discussion

Summary

This project helped improve the PC referral process at the OHSU Knight Cancer Institute outpatient clinics by identifying barriers to PC referral and staff knowledge gaps and sought to remedy them with an educational video. Utilizing Rosswurm and Larabee's model for change framework helped determine the direction of the project as both clinical expertise and context highlighted the underutilization of the nursing role in the referral process. This led to a nursing-specific survey to better understand why RNs were not regularly referring patients to PC as well as education targeted at addressing pertinent survey findings.

The survey results showed that while RNs understood the basic premise of PC they were not clear on their role in the referral process. Over half did not know it was within their scope of practice to independently refer patients to PC. Only 36.7% noted they felt comfortable discussing and referring patients to PC.

The survey also highlighted that RNs were more likely to discuss PC with patients than refer and that they felt most comfortable talking about PC in the context of symptom management. Over 80% of respondents stated they discussed PC with patients with poor symptom control. This comfort dropped markedly in the context of end-of-life discussions as just over half considered PC referral when asked questions about end-of-life planning by patients or their families.

The most noted barrier to PC referral was the misunderstanding that an oncologist's approval was needed for referral. RNs also indicated they wanted more information to feel comfortable recommending PC to patients and their families. This included a desire for a better understanding of PC to help explain its importance to patients and their families and dispel the myth that PC is synonymous with end-of-life care.

Though a referral algorithm was not created as part of this project, various considerations for PC referral were highlighted in the RN education. The video also discussed PC and its benefits, ways to bring up PC, RN ability to independently refer patients to PC, strategies for responding to emotion with empathy, and a step-by-step process for actually inputting the referral order into the electronic medical record. It remains to be seen if the video had an impact on staff knowledge regarding PC because a post-test survey was unable to be completed due to the coronavirus pandemic.

Particular strengths of this project included buy-in from key stakeholders, multiple targeted interventions, and the high survey response rate, as just under half of all clinic RNs responded.

Interpretation

The interventions served to increase the visibility of PC amongst RNs across the outpatient clinics. The pilot interviews helped determine the direction of the project by highlighting the opportunity presented through targeting RNs specifically. The survey created a forum for RNs to think about how PC fits into their role and workflow and also presented opportunities for growth within the system. It became clear from the survey that many RNs had an unclear understanding of existing clinic policies and felt they needed more PC education. The lacking knowledge surrounding clinic policy was reflected in RNs' perceived discomfort with referring patients to PC without first obtaining permission. To address this need, the education component of the project sought to standardize RN teaching about PC and related clinic policies.

Clinic data indicated that the average PC referral rate for patients with stage four lung cancer within 12 weeks of diagnosis over the past five quarters was 66.6%. While this number fell short of the 90% goal, it is actually much higher than what is seen in most studies. Sullivan

et al. (2019) for example, found that of 23,154 VA patients with advanced lung cancer just 57% received PC prior to death. It is possible that including the data for all patients with advanced cancer would lower the clinic referral rates but unfortunately this data is not tracked.

The survey results were congruent with many studies that examined nursing knowledge of PC. Previous studies have demonstrated that despite being a key part of the PC process, RNs believe their PC education is insufficient, leading to discomfort with integrating discussions about PC into their practice (Harden, Price, Duffy, Galunas, & Rodgers, 2017). Various studies have also examined the best way to provide RNs with PC education. Previous studies have successfully utilized education that involves both lectures and discussion groups with a combination of experiential and didactic learning (Harden et al., 2017). Unfortunately, such training was not possible as part of this project due to cost, lack of trainers, and staff availability.

Ultimately the education portion of the project was conducted as a 10-minute video, which likely lessened the impact of its benefit on staff. Moving the education platform from in-person to online was necessary due to the coronavirus pandemic but unfortunate as this made it difficult to determine the effect of the education on staff. The shift from in-person education to a video likely lessened the visibility of the project at the east Portland clinic. Fortunately, there were a few unexpected benefits of the video education. First, the video was sent to all clinic RNs, ultimately reaching a broader group than originally intended. Second, having recorded educational material created an opportunity for use in the onboarding process for new clinic RNs. The video and accompanying reference sheet are now part of the educational materials given to all new hires.

Limitations

This was a quality improvement project that was tailored to the specific needs of the OHSU outpatient community oncology clinics, which ultimately may not be the same as what other systems need to improve PC referrals. It is also possible that other systems are structured differently and do not allow for RN PC referrals, which limits the generalizability of components of the project.

Efforts were made to limit confounding bias. Multifaceted interventions were used to increase the likelihood that improvement in the referral process was due to the quality improvement project as opposed to chance. There were also no other projects involving PC occurring at the clinics at the time of this project.

One potential threat to internal validity was the survey design. Surveys were sent to all clinic RNs but did not require any identifying information which made it possible for a single RN to fill out multiple surveys. It is also possible that RNs discussed the answers to the PC knowledge section of the survey, as they were not specifically asked to take the survey in private. While there are a few validated PC nursing knowledge surveys, they rely heavily on end of life care and symptom management, so questions were used piecemeal, meaning the survey was not validated. The question asking about RN perceived barriers was free text and not required, which increased the risk of self-selection bias.

Perhaps the biggest limitation was the inability to perform in-person education and post-education testing at the east Portland clinic due to mandated social distancing because of the 2020 coronavirus pandemic. Instead of eliminating the educational component altogether, the decision was made to provide RN education in the form of a video. While this limited the opportunity to see if small group education made an impact at one particular clinic, it allowed for the RN education to reach all clinic RNs. The exact impact of this change remains to be seen.

Future Considerations

There are many opportunities for future research and quality improvement related to improving PC referrals at the OHSU community oncology clinics. One specific project would be post-education testing. This would help determine the impact of the educational video on staff RNs and their comfort with the referral process. Another opportunity would be focusing on continuing education for clinic RNs. Opportunities for future RN training could involve a referral algorithm should a short validated tool become available. Further clinic education for both RNs and non-RNs may also be valuable to improve the way PC is discussed with patients and their families across the clinic. Another area of research that could positively impact PC referrals is the patient and family perception of PC and exploration of the descriptions of PC that may resonate well with them. Overall there is ample opportunity for future projects to continue to positively impact early referrals to PC.

Conclusions

Advances in cancer treatment options have led to an increased need for urgent advanced care planning and symptom management in patients with newly diagnosed advanced cancer, which can be provided by PC specialists (Greer, Jackson, Meier & Temel, 2013; Parikh, Kirch, Smith, & Temel, 2013). Numerous studies of early incorporation of PC in patients with advanced cancer have demonstrated benefits ranging from improved quality of life to increased length of life (Ferrell et al., 2017). Though many organizations support integration of early PC alongside standard oncology care, a gap still exists between the evidence based guidelines and actual clinic practice, as was seen throughout the OHSU community oncology clinics.

This project sought to improve PC referrals in patients with advanced cancer at the OHSU community oncology clinics, specifically targeting the east Portland clinic. Informed by

Rosswurm and Larabee's model for change, this project was a multi-layered quality improvement project that ultimately focused on improving the RN role in the referral process. Each component of the project built on the next. Information from pilot interviews with key stakeholders helped determine the focus on RNs. Next, a targeted survey was sent to all clinic RNs to gain a better idea of current RN knowledge and referral patterns as well as perceived barriers to referral to PC. The survey highlighted that while RNs had a basic understanding of PC and its benefits, this understanding wasn't deep enough to routinely share with patients and their families and many didn't feel comfortable or know how to make independent referrals to PC. The survey findings ultimately informed an educational video that was sent to all clinic RNs to help improve the referral process.

While the education was originally intended as an in-person training, one of the benefits to the creation of the video was its potential to enhance the project's sustainability. Unlike in-person training, the video can be easily shared. Because of this, the video was modified slightly and is now part of the onboarding process for all new clinic RNs. The referral handout created for this project is also included in the clinic onboarding materials as well. Previous research has shown that continuing PC education is important in improving RN confidence and communication regarding PC (Harden, Price, Duffy, Galunas, & Rodgers, 2017). Thus, it is imperative that as time goes on, clinic RNs continue to feel supported in seeking PC education and in making PC referrals.

This quality improvement model could be used in other clinics and contexts to help improve PC referral processes. The benefit of the multi-layered approach was that the initial interviews helped determine the ultimate direction of the project by identifying what was uniquely useful to the practice setting. The model of utilizing interviews, a survey to determine

barriers and gaps in practice, and education to help overcome these gaps is easily adaptable.

Given the low percentage of early referrals to PC in patients with advanced and metastatic cancer, this project presents a framework to improve existing systems and ultimately an opportunity to help overcome barriers to referral in a population that would benefit from early PC.

References

- Buckley de Meritens, A., Margolis, B., Blinderman, C., Prigerson, H. G., Maciejewski, P. K., Shen, M. J., . . . Tergas, A. I. (2017). Practice patterns, attitudes, and barriers to palliative care consultation by gynecologic oncologists. *The American Society of Clinical Oncology*, *13*(9), e703-e711. doi:10.1200/jop.2017.021048
- Courteau, C., Chaput, G., Musgrave, L., & Khadoury, A. (2018). Patients with advanced cancer: When, why, and how to refer to palliative care services. *Current Oncology*, *25*(6), 403-408. doi:10.3747/co.25.4453
- Ferrell, B. R., Temel, J. S., Temin, S., Alesi, E. R., Balboni, T. A., Basch, E. M., . . . Smith, T. J. (2017). Integration of palliative care into standard oncology care: American Society of Clinical Oncology clinical practice guideline update. *Journal of Clinical Oncology*, *35*(1), 96-114. doi:10.1200/jco.2016.70.1474
- Finlay, E., Rabow, M. W., & Buss, M. K. (2019). Filling the gap: Creating an outpatient palliative care program in your institution. *ASCO Educational Book*, *38*, 111-121.
- Greer, J. A., Jackson, V. A., Meier, D. E., & Temel, J. S. (2013). Early integration of palliative care services with standard oncology care for patients with advanced cancer. *CA: A Cancer Journal for Clinicians*, *63*(5), 350-363. doi:10.3322/caac.21192
- Harden, K., Price, D., Duffy, E., Galumas, L., & Rodgers, C. (2017). Palliative care: Improving nursing knowledge, attitudes, and behaviors. *Clinical Journal of Oncology Nursing*, *21*(5), e232-238. doi.1188/17.cjon.e232-e238
- Hui, D. (2019). Palliative cancer care in the outpatient setting: Which model works best? *Current Treatment Options in Oncology*, *20*(17), 1-13. doi:10.1007/s11864-019-0615-8

- Hui, D., Hannon, B., Zimmermann, C., & Bruera, E. (2018). Improving patient and caregiver outcomes in oncology: Team-based, timely, and targeted palliative care. *CA: A Cancer Journal for Clinicians*, *68*(5), 356-376. doi:10.3322/caac.21490
- Hui, D., Kilgore, K., Park, M., Liu, D., Kim, Y. J., Park, J. C., . . . Bruera, E. (2018). Pattern and predictors of outpatient palliative care referral among thoracic medical oncologists. *The Oncologist*, *23*, 1230-1235. doi:10.1634/theoncologist.2018-0094
- Hui, D., Mori, M., Watanabe, S. M., Caraceni, A., Strasser, F., Saarto, T., . . . Bruera, E. (2016). Referral criteria for outpatient specialty palliative cancer care: An international consensus. *Lancet Oncology*, *16*, e552-559. doi:10.1016/s1470-2045(16)30577-0
- Institute of Medicine. (2014). *Dying in America: Improving quality and honoring individual preferences near the end of life*. Washington, DC: National Academy of Sciences.
- Kelley, A. S., & Morrison, R. S. (2015). Palliative care for the seriously ill. *New England Journal of Medicine*, *373*(8), 747-755. doi:10.1056/NEJMra1404684
- Lane, T., Ramadurai, D., & Simonetti, J. (2019). Public awareness and perceptions of palliative and comfort care. *The American Journal of Medicine*, *132*(2), 129-131.
<https://doi.org/10.1016/j.amjmed.2018.07.032>
- LeBlanc, T. W., Sederstrom, N., Spence, R., & von Roenn, J. (2017). Palliative care has come of age. *Journal of Oncology Practice*, *13*(9), 589-590. doi: 10.1200/jop.2017.026674
- Lupu, D. (2010). Estimate of current hospice and palliative medicine physician workforce shortage. *Journal of Pain and Symptom Management*, *40*(6), 899-911.
doi:10.1016/j.jpainsymman.2010.07.004
- National Consensus Project for Quality Palliative Care (2013). *Clinical practice guidelines for quality palliative care* (3rd ed.). Pittsburgh: Dahlin.

- Ogrinc, G., Davies, L., Goodman, D., Batalden, P. B., Davidoff, F., & Stevens, D. (2016). SQUIRE 2.0 (*Standards for Quality Improvement Reporting Excellence*): Revised publication guidelines from a detailed consensus process. *BMJ Quality and Safety*, *25*, 986-992.
- Palliative and Hospice Nursing Professional Issues Panel. (2017). *Call for action: Nurses lead and transform palliative care*. American Nurses Association.
- Parikh, R. B., Kirch, R. A., Smith, T. J., & Temel, J. S. (2013). Early specialty palliative care—Translating data in oncology into practice. *New England Journal of Medicine*, *309*(24), 2347-2351. doi:10.1056/NEJMs1305469
- Rosswurm, M. A., & Larrabee, J. H. (1999). A model for change to evidence-based practice. *Image- The Journal of Nursing Scholarship*, *31*(4), 317-322. doi: 10.1111/j.1547-5069.1999.tb00510.x
- Saga, Y., Enokido, M., Iwata, Y., & Ogawa, A. (2018). Transitions in palliative care: Conceptual diversification and the integration of palliative care into standard oncology care. *Chinese Clinical Oncology*, *7*(3), 32-42. doi:10.21037/cco.2018.06.02
- Schenker, Y., Crowley-Matoka, M., Dohan, D., Rabow, M. W., Smith, C. B., White, D. B.,... Arnold, R.M. (2014). Oncologist factors that influence referrals to subspecialty palliative care clinics. *Journal of Oncology Practice*, *10*(2), e37-e44. doi:10.1200/jop.2013.001130
- Shalev, A., Phongtankuel, V., Kozlov, E., Shen, M. J., Adelman, R. D., & Reid, M. C. (2017). Awareness and misperceptions of hospice and palliative care: A population-based survey study. *American Journal of Hospice and Palliative Medicine*, *35*(3), 431-439. <https://doi.org/10.1177/1049909117715215>

- Sullivan, D. R., Chan, B., Lapidus, J. A., Ganzini, L., Hansen, L., Carney, P. A.,...Slatore, C. G. (2019). Association of early palliative care use with survival and place of death among patients with advanced lung cancer receiving care in the Veterans Health Administration. *JAMA Oncology*, e1-8. doi:10.1001/jamaoncol.2019.3105
- Temel, J. S., Greer, J. A., Muzikansky, A., Gallagher, E. R., Admane, S., Jackson, V. A., & Lynch, T. J. (2010). Early palliative care for patients with metastatic non-small-cell lung cancer. *New England Journal of Medicine*, 363(8), 733-742. doi:10.1056/NEJMoa1000678
- Vital Talk. (2019). *Responding to emotion: Respecting*. Vital Talk. <https://www.vitaltalk.org/guides/responding-to-emotion-respecting/>
- White, K. M. (2015). Evidence-based practice. In S. Dudley-Brown, K. M. White, & M. F. Terhaar (Eds.), *Translation of evidence into nursing and health care* (pp. 3-24). New York: Springer Publishing Company.
- Zimmermann, C., Swami, N., Krzyzanowska, M., Leighl, N., Rydall, A., Rodin, G., . . . Hannon, B. (2016). Perceptions of palliative care among patients with advanced cancer and their caregivers. *CMAJ*, 188(10), e217-e227. doi:10.1503/cmaj.151171

Appendix A

Survey Sample Characteristics (n=30)

CHARACTERISTIC	n
Role	
Triage RN	2
Infusion RN	20
RN Navigator	6
Other (triage + infusion & management)	2
Education	
LPN	0
BSN	26
MSN	2
Other (ASN & AA)	2
Oncology Certification	
Yes	16
No	14
Years in practice as a nurse	
<1 year	0
1-3 years	0
3-5 years	3
5-10 years	11
> 10 years	16
Years in oncology practice	
<1 year	2
1-3 years	4
3-5 years	2
5-10 years	8
> 10 years	14
Specialized PC education?	
Yes	7
No	23

Appendix B

Palliative Care Knowledge (n=30)

KNOWLEDGE	n
PC is different from traditional care because PC:	
is curative	0
is equivalent to hospice care	0
is focused on comfort	29
is equivalent to end of life care	1
withdraws care	0
I don't know	0
Which of the following members of the healthcare team are important to the delivery of PC?	
Physicians	0
Nurses	1
Social Workers	0
Advanced practice providers	0
Physical and occupational therapists	0
All of the above	29
PC should only be provided for patients who have no curative treatments available	
True	1
False	29
PC is not compatible with curative treatment	
True	1
False	28
PC is only appropriate in situations where there is evidence of a downward trajectory or deterioration	
True	1
False	29
It is important to incorporate PC early in patients with metastatic cancer	
True	1
False	29
PC referral should only be considered when a patient has exhausted their cancer treatment options	
True	1
False	29
Patients receiving radiation for palliation of symptoms are not candidates for PC	
True	1

False	29
PC benefits include enhanced quality of life for the patient and family	
Strongly disagree	0
Disagree	0
Neutral	0
Agree	4
Strongly agree	26
PC benefits include expert pain and symptom management	
Strongly disagree	0
Disagree	0
Neutral	1
Agree	5
Strongly agree	24
Patients or families are unwilling or unready to utilize PC services	
Strongly disagree	0
Disagree	8
Neutral	11
Agree	11
Strongly agree	0

Appendix C

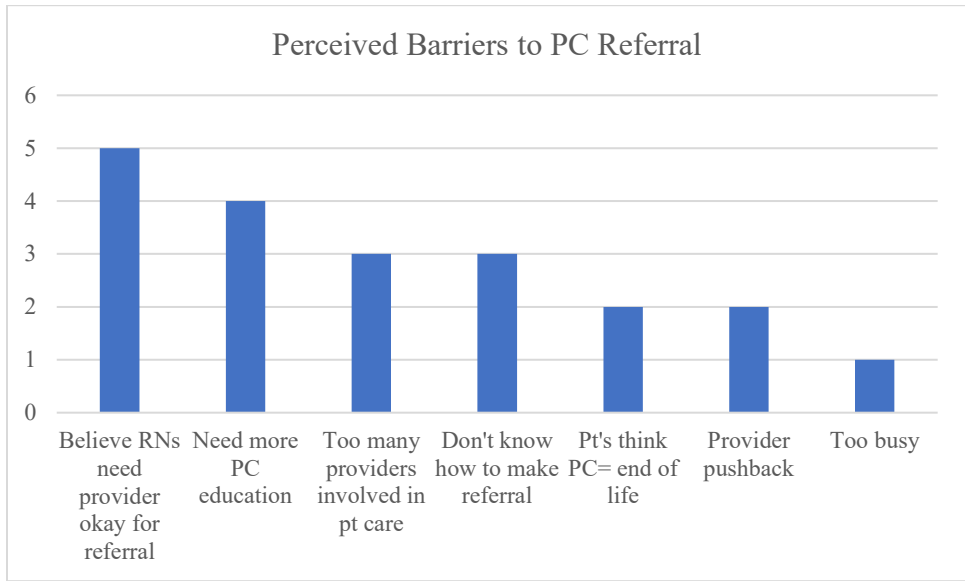
Palliative Care Referral Knowledge & Comfort (n=30)

REFERRAL	n
As a nurse, I am able to refer patients with metastatic cancer to PC without first checking with their oncologist	
Strongly disagree	4
Disagree	6
Neutral	5
Agree	8
Strongly agree	7
As a nurse, I am able to refer any oncology patient to PC without first checking with their oncologist	
Strongly disagree	4
Disagree	7
Neutral	5
Agree	7
Strongly agree	7
I don't feel comfortable referring patients to PC without provider permission	
Strongly disagree	5
Disagree	6
Neutral	6
Agree	9
Strongly agree	4
I never refer patients to PC	
Strongly disagree	7
Disagree	7
Neutral	6
Agree	7
Strongly agree	3
I rarely refer patients to PC	
Strongly disagree	6
Disagree	5
Neutral	5
Agree	10
Strongly agree	4
I consider and refer patients to PC	
Strongly disagree	3
Disagree	7

Neutral	9
Agree	6
Strongly agree	5
I discuss PC with patients if they are experiencing poor symptom control	
Strongly disagree	0
Disagree	1
Neutral	4
Agree	13
Strongly agree	12
I only consider referring patients to PC if they have poor control of more than one symptom	
Strongly disagree	6
Disagree	15
Neutral	4
Agree	5
Strongly agree	0
I consider referring patients to PC if they or their family members ask questions about the end of life	
Strongly disagree	1
Disagree	4
Neutral	8
Agree	10
Strongly agree	7
I consider referring patients to PC if they have poor control of any of the following symptoms (check all that apply)	
Pain	27
Tiredness	17
Nausea/vomiting	19
Depression	23
Anxiety	22
Drowsiness	11
Appetite	22
Wellbeing	22
Shortness of breath	16
Other:	0
I don't refer patients to PC for poor symptom control	3

Appendix D

RN Perceived Barriers to PC Referral



How RNs Discuss PC with Patients and Families

