

UNIVERSITY OF CALIFORNIA

Los Angeles

Improving the Early Integration of Pediatric Palliative Care

A dissertation submitted in partial satisfaction of the
requirements for the degree
Doctor of Nursing Practice

by

Marché Arnold

2024

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ABSTRACT OF THE DISSERTATION

Improving the Early Integration of Pediatric Palliative Care

by

Marché Arnold

Doctor of Nursing Practice

University of California, Los Angeles, 2024

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Background: Many professional organizations have recommended early pediatric palliative care involvement for terminally ill children, and it has been shown to improve patient outcomes and quality of life. However, many pediatric intensive care units and providers underutilize this valuable service or delay consultation until the end of life. **Objectives:** To examine the impact of an educational intervention and implementation of a RN rounding tool and pediatric palliative care screening tool (Pediatric Palliative Screening Scale [PaPaS]) on the rates of palliative care

referrals (three months pre- and three months post-intervention). **Methods:** A pre-and post-design QI project was conducted for registered nurses, nurse practitioners, and medical providers in a 24-bed Pediatric Intensive Care Unit and 6-bed Step-Down Unit at a major academic medical center. **Results:** The findings showed an increase in overall referrals post-intervention [pre-11 vs. post-16; 45% change] and new referrals [pre-6 vs. post-16; 150% change]. Unit-based referrals demonstrated a 43% increase in PICU referrals and a 50% increase in DOU referrals. There was no significant difference between groups related to age and sex. There was a statistically significant difference in diagnosis between groups with the pre-intervention group predominantly brain (45.5%), cancer (27.3%), and cardiac (18.2%), and the post-intervention group cardiac (33.3%), liver (18.8%) and syndrome (18.8%) acute and chronic conditions ($p=.040$). Out of the 19 completed PaPaS scales, 14 scores (15-27) indicated the need to initiate a PPC referral. **Conclusion:** Despite the limited use of the screening tool, there was an increase in new referral patterns, which may have been influenced by the education on palliative care recommendations and the benefit of early referral. With provider workload challenges in many pediatric intensive care units, ongoing educational reminders may be key to keeping early palliative care referrals at the forefront of daily patient care.

The scholarly project of Marché Arnold is approved.

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2024

DEDICATION

This scholarly project is dedicated to my daughter, Lucia. You have always been and always will be my greatest source of joy, my most beautiful blessing, and my motivation for all that I do. Mommy will always love you. To my parents, Evelia and Howell, thank you for always being my biggest support throughout all of life's endeavors and challenges. Thank you for always believing in me and instilling the importance of faith and education. I would not be who I am today if it were not for your unconditional love and support. To Liesl, you are my sister and best friend. Thank you for being the calm in my storm, for providing me with laughter and solace when we are together, and for always being there. I hope we are sisters in every lifetime. To the rest of my family, friends, colleagues, professors, and committee members, thank you for all the support and words of encouragement. I truly could not have accomplished this success without you.

Always believe in yourself, and always believe in prayers.

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I would like to acknowledge Jeannie Meyers, CNS, who served as my clinical mentor throughout the duration of this project. I am honored to have met and worked with such a distinguished and knowledgeable palliative care expert. Thank you for helping develop the project design, facilitating the buy-in of key stakeholders, and assisting with data extraction.

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At UCLA Ronald Regan Medical Center, I would like to express my deep appreciation for Heather Van Dongen-Trimmer, DNP, and Dr. Ratna Behal for welcoming me and my scholarly project into the pediatric palliative care team and pediatric intensive care unit. Thank you for helping with the project's design, facilitating the buy-in of key stakeholders, and assisting with data extraction.

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VITA

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CHAPTER ONE: INTRODUCTION

The Pediatric Intensive Care Unit (PICU) is the most common location for pediatric deaths in the United States (U.S.), and about 30-60% of PICU deaths involve the withdrawal of one or more forms of life-sustaining therapy (Short & Thienprayoon, 2018; Nicoll, 2022). Research conducted in the U.S. has revealed that only 10 to 15% of children who die receive pediatric palliative care consultation (PPC), and about 20% of U.S. Children's hospitals lack a PPC program (Friebert, 2019; Humphrey, 2022). Consultation with PPC in PICUs has been associated with reduced deaths in the PICU and shorter hospital stays (Lutmer et al., 2016; Nicoll et al., 2022; O'Keefe et al., 2021). However, consistent evidence has emphasized that despite the known importance of early integration of PPC, PICU providers often delay PPC consultation until the end of life, the occurrence of exacerbated symptom burden, or when cases are deemed complex or challenging (Carter et al., 2022; Cuviallo, Yip, et al., 2021; Richards et al., 2018).

PPC is a specialized form of healthcare that focuses on improving the quality of life and alleviating suffering for children and adolescents with life-limiting or life-threatening conditions, frequently encompassing end-of-life care (Lysecki et al., 2022). PPC teams are multidisciplinary and can encompass a range of professionals, including doctors, nurse practitioners (NPs), physician's assistants, nurses, social workers, child life specialists, bereavement counselors, spiritual care advisors, pharmacists, psychologists, administrators, and various others (Lysecki et al., 2022). PPC often utilizes an interdisciplinary team approach that facilitates psychosocial and medical support services, sibling support, spiritual guidance, and goal-oriented medical therapies (Lysecki et al., 2022; Rogers et al., 2021).

Research findings have consistently demonstrated that the early integration of PPC (i.e., PPC consultation at the time of life-threatening or life-limiting diagnosis) improves various aspects of patient care and patient outcomes. These benefits of PPC include improved quality of life, enhanced communication between healthcare providers and families, decreased hospitalizations, decreased emergency department (ED) visits (Rogers et al., 2021), fewer pediatric intensive care unit (PICU) admissions (Friedrichsdorf et al., 2019), shorter lengths of stay (LOS) (Bower et al., 2022), advanced care planning and end-of-life support, improved symptom management (CuvIELLO et al., 2021), emotional support for both patients and their families (Walter et al., 2019), and decreased in-patient deaths (Lysecki et al., 2022). Furthermore, the early integration of PPC fosters strong relationships between the healthcare team and families, smooth transitions of care, and trust between healthcare providers and families when making end-of-life decisions. It also facilitates adopting a family-led approach to patient-centered care (Linebarger et al., 2022).

There are various barriers to the early integration of PPC, mainly related to delays in PPC referrals. One of the most common barriers revealed in the literature suggests that the delay in PPC referrals is heavily influenced by subspecialists' negative perceptions of PPC (CuvIELLO, Raisanen, et al., 2021; Laronne et al., 2021). Research highlights that it is common for many subspecialists to lack familiarity with palliative care, struggle with determining appropriate referral timing, confuse palliative care with hospice services, worry about upsetting families, experience discomfort discussing death and dying, or perceive referrals to palliative care as professional failures (CuvIELLO, Raisanen, et al., 2021; Dalberg et al., 2013; Keele et al., 2016; Laronne et al., 2021; Walter et al., 2021). Missed and delayed referrals contribute to invasive medical interventions and increased in-hospital deaths (Humphrey, 2022; Salins et al., 2022).

Insufficient standardization and documentation of the referral process hinder the effective integration of PPC.

To address the specific barrier of unfamiliarity or discomfort with counseling or managing children in palliative care, the American Academy of Pediatrics ([AAP], 2000) recommends early consultation with pediatric hospice care or PPC at the time of diagnosis of a life-threatening or terminal condition. The American Society of Clinical Oncology (ASCO), the World Health Organization (WHO), and the American College of Critical Care Medicine (ACCCM) also recommend that PPC should be provided from the time of life-threatening or life-limiting diagnosis and maintained throughout the course of the illness, irrespective of the outcome (Cuvillo, Yip, et al., 2021; Short & Thienprayoon, 2018).

Despite the well-established benefits of PPC and recommendations from professional organizations, there is a significant gap between the need for and the availability of PPC and the utilization of PPC services. This gap in the integration of PPC among pediatric patients requiring intensive care has led to the development of the following PICO question for this Doctor of Nursing Practice (DNP) scholarly project: For children admitted to the pediatric intensive care unit (PICU), what is the effect of using the Pediatric Palliative Screen Scale (PaPaS scale) and provider education, as compared to standard care, on the rate of pediatric palliative care (PPC) referrals, three months pre- and post-intervention?

Addressing the delayed integration of PPC in chronically, terminally ill, or critically ill pediatric patients is imperative to ensure comprehensive support and enhance the quality of life for this vulnerable population. This paper will discuss the early integration of PPC as the end goal for the quality improvement (QI) project. Early integration of PPC will be accomplished through improved PPC referral rates in the PICU.

CHAPTER TWO: THEORETICAL FRAMEWORK

The Change Theory, developed by Kurt Lewin (1947), a pioneer in social psychology, presents a comprehensive framework for understanding and facilitating change in various contexts, including healthcare. This theory revolves around a three-stage model known as the "unfreezing-change-refreeze" model, which involves a dynamic process of shifting behavior and establishing new patterns. Central to Lewin's theory is the concept of behavior as a dynamic balance between opposing forces.

The Change Theory by Lewin (1947) consists of three major concepts: driving forces, restraining forces, and equilibrium. Driving forces promote change by influencing individuals or groups toward desired outcomes. They represent the motivations and incentives for change. Conversely, restraining forces are obstacles or factors that hinder change and influence individuals or groups away from change. Equilibrium is the state where the driving forces are balanced with the restraining forces, resulting in no significant change. The theory suggests that change occurs when the balance between these forces shifts. An illustration of this theory can be found in Appendix A.

The Change Theory's application to the project's development is evident in its driving and restraining forces construct. In the context of the DNP project, driving forces include recognizing the benefits of early integration of pediatric palliative care (PPC) and the desire to enhance the quality of care for critically ill children. These forces push for change by highlighting the importance of overcoming barriers and resistance. Restraining forces may include challenges associated with changing established practices, lack of awareness about the benefits of PPC, or resistance to adopting new approaches.

The project aligns with the stages of the Change Theory. The first stage, "unfreezing," involves creating conditions that allow individuals or groups to let go of old patterns and beliefs. In the DNP project, this corresponds to overcoming the barriers and resistance to early PPC integration. The DNP project aims to increase the driving forces by using the PaPaS scale as a tool to identify patients who may benefit from PPC, thereby shifting the equilibrium towards change.

The second stage, "change," entails the actual process of adopting new behaviors or practices. This aligns with the project's implementation of the PaPaS scale and the subsequent early integration of PPC in the PICU. The project aims to facilitate a shift in behavior and practice by utilizing the driving forces to overcome the restraining forces.

The "refreezing" stage involves solidifying the change as the new norm or standard practice. This corresponds to establishing the early integration of PPC as a routine practice in PICUs, ensuring that the benefits of PPC become an integral part of patient care.

The Change Theory provides a structured framework for understanding the dynamics of change and facilitating its implementation in healthcare settings. The constructs of driving forces, restraining forces, and equilibrium offer valuable insights for guiding the project's development by highlighting the factors that promote or hinder the early integration of PPC. The unfreezing, change, and refreezing stages align with the project's objectives and processes, ultimately improving the quality of care for children admitted to the PICU and their families.

CHAPTER THREE: REVIEW OF LITERATURE

An in-depth literature review was conducted to evaluate current evidence and knowledge regarding PPC screening tools in the PICU setting and if screening increases referrals. The following databases were used: Cumulative Index to Nursing and Allied Health Literature

(CINAHL) and PubMed. Search terms and Boolean operators included “pediatric intensive care unit OR picu OR pediatric critical care,” “palliative care OR end of life care OR hospice care,” “pediatric palliative care,” “screening OR assessment OR test OR diagnosis,” and “Pediatric Palliative Screening scale,” AND “referral OR consultation” were used. Publication dates were limited to the past five years (2018-2023) and limited to the English language. A total of 302 articles were yielded, but very few pertained to the PICO question above. Therefore, publication dates were expanded to the past ten years (2013- 2023). This expansion then yielded a total of 456 articles. The titles and abstracts of these articles were screened, and duplicates were removed. Articles were eliminated if they did not pertain to the pediatric population, the assessment tool did not directly evaluate the need for PPC, or if the intervention being tested was not a screening tool or education. 13 articles were extracted for full-text review. A PPC assessment tool was identified among the articles in the final review.

The literature search yielded six articles that support interventions to improve the early integration of PPC services through the early identification of eligible patients via screening tools and PPC education. These articles are presented in a Table of Evidence.

Cuviello, Raisanen, et al. (2021) conducted a mixed-methods study to explore the patient characteristics used by pediatric oncology providers to trigger PPC referrals and identify ways to improve PPC integration in the care of children with cancer. The study involved semi-structured qualitative interviews with 77 pediatric oncology interdisciplinary team members from two major academic institutions in the U.S. The interviews were conducted over three months, focusing on integrating PPC in pediatric oncology. The interviews discussed PPC consultation frequency, timing, triggers, and clinical case scenarios. Participants estimated PPC consultation rates for their patients and identified initiating team members. They discussed patient, family,

and disease characteristics that trigger PPC consultation. Clinical case scenarios were presented, each with predetermined triggers, and participants were asked if they would consult PPC in those scenarios and why. Conventional content analysis was applied to interview transcripts, involving coding and grouping responses into themes. Findings suggest that participants estimated that fewer than 50% of their patients received care from the PPC team, indicating inconsistent referral practices for PPC. Among participants who requested a PC consultation, 75% felt that the timing of the PPC consultation was too late in the patient's disease course. 98% of study participants expressed the need for improving PPC integration into the care of their pediatric oncology patients, emphasizing the importance of enhancing PPC recognition and utilization. Three main themes for achieving early PPC integration emerged from the qualitative data: 1) improving communication, 2) providing education, and 3) overcoming system barriers. These barriers included a shortage of PPC resources, insufficient methods for recording crucial discussions or patient preferences concerning end-of-life care, and a lack of standardization, including the absence of a screening tool to guide PPC consultations. Many participants reported knowledge deficits about available PPC team resources and were unclear about the potential benefits of a PPC consult. Only 44% of participants had received some form of formalized PPC training. Over 80% of participants expressed support for the effectiveness of a screening tool for palliative care consultations, indicating that implementing a standardized approach could improve the early identification of patients who would benefit from PPC and enhance the utilization of PPC. Participants recommended including characteristics such as poor prognosis, uncontrolled symptoms, comorbidities, poor coping, experimental or intense therapy, and high-risk disease in the screening tool triggers for PPC consultation.

The study conducted by Newton and Sebbens (2020) aimed to investigate the impact of educational sessions and established guidelines on PC referrals for children managing life-limiting illnesses. The study was a single-center project conducted at a large pediatric hospital in Dallas, Texas, involving 64 participants from various departments, including the neonatal intensive care unit (NICU), PICU, and Center for Cancer and Blood Disorders (CCBD). Educational sessions were designed based on information processing theory, incorporating referral guidelines from the AAP and National Hospice and Palliative Care Organization (NHPCO), along with institutional policies. The authors and PPC department stakeholders designed pre- and post-surveys for the study. The pre-survey gathered demographic data, comfortability with palliative care referral on a 6-point Likert scale, and the number of personal PPC referrals placed within the last year. A 15-minute educational session that reviewed established palliative care guidelines was held twice daily for one week in each unit. Participants were given four questions related to the presented material to assess knowledge after the presentation. Results showed that 90.5% (n=58) answered question one correctly, 98.4% (n=63) answered question two correctly, 70.3% (n = 45) answered question three correctly, and 85.9% (n = 55) answered question four correctly. Overall, participants displayed a robust comprehension of the organization's recommendations and guidelines, evident from the significant number of accurate responses. In the post-survey, 55 participants ranked the value of the information received about PC on a Likert scale from 0 to 5, with a mean score of 4.65 [standard deviation (SD) 0.552], indicating that they found the information valuable to their personal practice. Fifty-four participants ranked their likelihood of making a referral to PPC based on the information provided, with a mean score of 4.52 [SD 0.666], indicating they were more likely to refer to PPC after the educational intervention. Common reasons for not referring

included knowledge deficits about qualifying criteria and how to place referrals, and parental refusal. Hospital-wide referrals increased from a monthly average of 13.5 to 22.0 [SD 2.121 and 5.657]. The study suggests that educational interventions can impact PPC referrals and provider comfortability.

The study by Lafond et al. (2022) aimed to enhance primary PPC skills and confidence among frontline clinicians caring for seriously ill pediatric patients. Using a descriptive correlational pretest/posttest longitudinal design, the project was conducted over four years at a 323-bed urban children's hospital in the mid-Atlantic region of the U.S. Participants included various English-speaking interprofessional members that provided care for critically ill children such as physicians, advanced practice registered nurses (APRNs), physician assistants (PAs), registered nurses (RNs), pharmacists, patient care technicians, social workers, child life specialists, chaplains, volunteers, and case managers. In the 3rd year, the project expanded to include community hospice partners and regional pediatric programs. Of 220 applicants, 209 participants completed the year-long educational program, featuring didactic sessions, mentoring, and quality improvement projects. The intervention addressed clinicians' perceived barriers, such as limited time for in-depth discussions and inadequate PPC availability. The year-long program comprised an initial 2-day workshop, self-study modules, quarterly educational seminars, and a culminating 1-day workshop, supplemented by monthly mentoring sessions. Data were collected through instruments like the PANDA Cubs Application, Moral Distress Questionnaire-Pediatric, and ANCC Educational Design Evaluations. Results indicated substantial improvements, with participants reporting increased comfort in having difficult conversations, enhanced end-of-life care comfort (89.5%), knowledge (94.7%) and skills (100%), improved communication (100%), and improved preparedness to discuss and access

PPC resources (100%). Most notably, there was a 33% increase in PPC consults, a 98% increase in integration for high-risk cancer patients, and a 52% increase in total PPC team encounters. This project demonstrated the potential for education and mentoring to strengthen primary PPC, alleviate moral distress, and increase referrals to specialty PPC.

Shaw et al. (2018) conducted a pilot QI project to address a gap in care for pediatric patients with life-limiting and life-threatening illnesses by developing and implementing a nurse-driven PPC screening tool to facilitate communication between bedside registered nurses and the PPC team. The assessment tool was created after using symptoms identified by the Standards of Practice for Pediatric Palliative Care and Hospice, the Institute of Medicine report called *When Children Die*, and a PPC chart review. This tool has three domains: 1. Chronic Complex, Life-Threatening, or Life-Limiting Diagnosis, 2. Symptom present and Poorly Controlled, 3. Distress. The third domain, Distress, addressed two topics: Family/Patient Concern and Nurse Concern. This project occurred in a 60-bed pediatric acute care unit at an academic-level IV trauma center in central Virginia over four weeks. The developed screening tool assessed patients' symptom profiles and the need for PPC consultation. Patients meeting one or more criteria warranted a PPC referral. Descriptive statistical methods, such as frequency tables, cross-tabulations, and chi-square analysis, were used for data analysis. Fifty-three patients were identified as meeting the diagnostic criteria for PPC consultation. Of these patients, 49% had uncontrolled symptoms, 51% had nurse concerns, and 55% had patient/family concerns. Only six of the 53 patients identified as meeting the diagnostic criteria had a PPC consultation. Statistically significant relationships were found between PPC team involvement and reductions in symptom burden and nurse concerns ($p < 0.05$). Patients who received a palliative care consultation had significantly lower rates of dyspnea ($p = 0.003$), constipation ($p = 0.000$), family concern ($p = 0.009$), and

nurse concern ($p = 0.012$) compared to those without a consultation. This QI project demonstrated that the screening tool was selective in identifying patients with excessive symptom burden in a life-threatening or life-limiting illness while not overwhelming the palliative care team with excessive and unnecessary referrals. Notably, this screening tool has yet to have established validity and reliability.

A 9-month prospective interventional QI study by Lutmer et al. (2016) aimed to assess the impact of PPC screening criteria on access to PPC services in the PICU and investigate the relationship between PPC team involvement and intensive care unit (ICU) and hospital (length of stay (LOS)). Stakeholders from the Pediatric Critical Care Medicine (PCCM) and PPC teams collaboratively established unit-specific PPC screening criteria. Due to the lack of specific PPC consultation criteria for the PICU, a pilot phase was initiated to test criteria without actively seeking referrals. The initial criteria encompassed broad diagnostic categories, medical technology dependence, prolonged PICU stays, and frequent admissions. During a one-month pilot, 33% of admissions met these criteria, suggesting the potential for over 800 PPC consultations annually, a significant increase compared to previous years. However, the screening process showed poor specificity in identifying patients with genuine PC needs. Consequently, the criteria were refined based on outcome data and existing literature, focusing on chronic life-limiting conditions, specific diagnoses, poor prognoses, and severe medical situations such as ECMO use, brain injuries with risk of persistent vegetative state, certain neurologic conditions combined with acute respiratory failure, specific oncology categories, severe metabolic diseases, chromosomal abnormalities, renal replacement therapy, and fulminant hepatic failure. Additionally, criteria were established for PC referrals based on parental or team assessment of need or prior PC service involvement. All patients admitted to the PICU during the

study period were screened for PPC eligibility. Patients were eligible for inclusion if PPC referrals were requested while they were physically in the PICU, excluding cases where PPC referrals had been made prior to PICU admission within the same hospitalization. A clinical nurse leader (CNL) screened the PICU census daily and recorded all eligible patients. Any concerns regarding screening criteria interpretation were discussed with PPCM or PPC faculty. Patients were assigned a primary trigger based on the most pertinent criterion, even if they met multiple triggers. The PPC referral rate was based on recorded referrals by the CNL, which were discussed with the attending physician (AP) during rounds. The referral remained at the discretion of the AP. Following the implementation of the screening criteria, findings demonstrated that PPC consultation rates had increased, with 5% of PICU admissions receiving PPC consultation in the first quarter of 2014. Among the 100 identified patients eligible for PPC services, 70% received referrals, and 100% of the referrals led to PPC consultations. Approximately 66% of the referred patients were new to the PPC team. Patients with an existing PPC relationship were more likely to have a ventriculoperitoneal shunt and have limitations of medical interventions in place. Patients who did not receive a consultation for PPC had a higher likelihood of dying in the PICU, with a rate of 40%, as opposed to those who had a consultation with PPC services, with a rate of 8%. Notably, the patients with an existing PPC relationship represented the largest group of eligible referrals (27%), with referrals requested for 89% of them. 15% of all referrals were based on recommendations from the healthcare team or parents. Compared to patients already established with PPC services, those newly referred to PPC encountered a longer delay in PC consultation. Newly referred patients also had 2.2 times longer PICU stays. The study described the effectiveness of PPC screening criteria in improving access to PPC services in the PICU.

Bergstraesser et al. (2013) conducted a qualitative study to inform the development of a screening tool called the Pediatric Palliative Screening Scale (PaPaS Scale) for pediatricians to enhance the timely recognition of children who could benefit from PPC. Face-to-face semi-structured interviews were conducted with seven internationally renowned PPC experts from the United Kingdom, France, the United States of America, and Canada, while eleven pediatric health professionals from the University Children's Hospital in Zurich participated in the subsequent focus group discussion. This study's initial phase aimed to develop a clinical tool for improved referrals to PPC. The process encompassed three stages: first, creating a model from evidence and expert insights; second, expanding the model through expert interviews and a focus group discussion with PPC providers and users; and third, assessing face and content validity. Version 1 of the PaPaS scale expanded upon the categorization framework established by Together for Short Lives, previously known as ACT. Expert interviews and focus group discussions refined the instrument into Version 2 and Version 3. Thematic analysis revealed five key domains related to identifying children with life-limiting diseases who may benefit from PPC: 1) trajectory of disease and impact on daily activities of the child; 2) expected outcome of disease-directed treatment and burden of treatment; 3) symptom and problem burden; 4) preferences of patient, parents, or healthcare professional; and 5) estimated life expectancy. These five domains contain a set of questions, and each question carries a specific weight and score based on the response. The cumulative score obtained from the assessment helps categorize patients into different courses of action. A score of 25 or above indicates that PPC is warranted for the identified patients. In cases where palliative care is deemed necessary, a stepwise or graduated approach to its introduction would be implemented. This study represents an initial

report regarding the development of a screening tool aimed at promoting the timely integration of PPC within the disease progression of critically ill children.

Synthesis of Literature Review

This literature synthesis examines six articles that focus on interventions to enhance early PPC integration through the early identification of eligible patients via screening tools and PPC education. While the studies share the overarching goal of improving PPC utilization, they vary in focus, methodology, and outcomes.

Similarities

Some common characteristics of the selected studies included hospital-based locations and predominantly qualitative or mixed-methods designs. Most of the studies were conducted in the U.S., except for the seminal study that led to the development of the PaPaS scale, which was conducted in Switzerland. Two of the six studies were conducted in the PICU (Lutmer et al., 2016; Shaw et al., 2018), and all were conducted in the pediatric population.

Two interventions were found to improve the early integration of PPC and improve PPC referral rates: PPC education and the implementation of screening tools. CuvIELLO, Raisanen, et al. (2021) utilized qualitative interviews to identify barriers to timely PPC referrals, emphasizing the need for improved education and suggested the use of a screening tool. Lafond et al. (2022) emphasize the role of education and mentoring in enhancing primary PPC skills among frontline clinicians, leading to increased referrals and encounters with the PPC team. Similarly, Newton and Sebbens (2020) assessed the impact of educational sessions that overviewed guidelines for PPC referrals and institutional policies, revealing that participants found the education sessions valuable and were more likely to refer to PPC after the intervention. Newton and Sebbens (2020) and Lafond et al. (2022) demonstrated that providers attested that PPC educational intervention

improved their comfort and likelihood of referring to PPC; both studies demonstrated increased referral rates post-intervention.

Various studies developed or evaluated screening tools to aid in the early identification of pediatric patients who would benefit from PPC. These studies yielded promising results in accurately identifying patients who may benefit from PPC and have demonstrated increased PPC referrals (Bergstraesser et al., 2013; Lutmer et al., 2016; Shaw et al., 2018). Both tools developed by Bergstraesser et al. (2013) and Shaw et al. (2018) utilized domains to categorize criteria, and all three of the tools (Bergstraesser et al., 2013; Lutmer et al., 2016; Shaw et al., 2018) used symptomatology and family or healthcare staff concerns as criteria. The assessment tools by Bergstraesser et al. (2013) and Shaw et al. (2018) were developed using evidenced-based literature such as standards of practice and guidelines published by professional organizations.

Differences and Contradictions

The selected articles on PPC utilization and screening tools demonstrate differences and contradictions in their findings. One notable difference is the variation in study designs, with some articles utilizing qualitative approaches (Cuviallo et al., 2021) or interventional QI projects (Newton & Sebbens, 2020; Shaw et al., 2018). Methodological differences may contribute to discrepancies in the reported rates and trends of PPC consultations and the effect of PPC education. Newton & Sebbens's (2020) implementation phase was one week, whereas the study by Lafond et al. (2022) was one year. The content and methodology of education also varied among Newton and Sebbens (2020) and Lafond et al. (2022). The content of Newton and Sebbens (2020) focused on established PPC guidelines, and each educational session was 15 minutes long. In comparison, the duration of the educational intervention of the study by Lafond et al. (2022) was one year, and the content of the educational sessions encompassed various

topics such as principles and goals of PPC, symptom management, bereavement, developmental considerations in pediatric care, ethical and legal challenges, communication, and end of life care.

Shaw et al. (2018) and Lutmer et al. (2016) implemented a nurse-driven tool, while the PaPaS scale was designed to be provider-driven. The assessment tools by Bergstraesser et al. (2013) and Shaw et al. (2018) were developed using evidenced-based literature such as standards of practice and guidelines published by professional organizations. The PaPaS Scale was initially developed based on a categorization framework and then was refined after clinical expertise from several PPC healthcare professionals and PPC experts. The Shaw et al. (2018) assessment tool encompassed three domains, whereas the PaPaS scale had five domains. Lutmer (2016) did not specify the presence of established categories or domains but instead developed unit-specific criteria. The assessment tools by Shaw et al. (2018) were completed by bedside RNs three days a week, while the assessment tools by Lutmer (2016) were completed by a CNL daily.

Shaw et al. (2018) and Lutmer (2016) evaluated the impact of assessment tools on PPC referrals, while Bergstraesser et al. (2013) focused on the development of a tool and did not assess its impact on PPC referrals. Shaw et al. (2018) demonstrated that 11% of patients identified as meeting the diagnostic criteria received a PPC consultation. In comparison, results from Lutmer (2016) demonstrated that 70% of patients who were identified as meeting the diagnostic criteria received a PPC consultation. Contradictions are limited, as the studies collectively highlight the value of PPC education and screening tools to improve the early integration of PPC.

CHAPTER FOUR: METHODS

Study Design

This quality improvement (QI) project was a pre- and post-intervention design to evaluate the impact of a pediatric palliative care (PPC) educational intervention and the use of the Pediatric Palliative Screening Scale (PaPaS) to facilitate early PPC referrals in the PICU setting.

Ethical Considerations

The Institutional Review Board (IRB) deemed this QI project to be exempt as no identifying information was collected. The intervention for this QI project involved educational sessions that were administered to physicians, nurse practitioners (NPs), registered nurses (RNs), and managers and the implementation of the PaPaS screening tool. Permission to use the PaPaS Scale was obtained prior to the initiation of this project (Appendix B).

Sample and Setting

Participants included RNs, resident physicians, NPs, and children identified as meeting PPC referral criteria as indicated by the PaPaS scale (Appendix C). This QI project was conducted in the main 24-bed PICU and the 6-bed Direct Observation Unit (DOU) within a large, academic-level children's healthcare medical center in Southern California.

Procedure

Educational Intervention

The educational intervention for this QI project included a 20-minute PowerPoint presentation that was administered by the QI project lead to the nurse managers, RNs, NPs, and physicians of the PICU during staff meetings. The content covered included a definition of PPC, review of the background and significance of delayed PPC referrals, the purpose of the QI project, the benefits of PPC, and an overview of the RN rounding tool and PaPaS scale.

RN Rounding Tool

After the educational sessions had been completed, copies of the RN rounding tool affiliated with the project (Table 1) were placed at each RN charting cubicle in the PICU and DOU. Key components in the RN rounding tool included serious illness or life-threatening diagnoses, mechanical ventilation exceeding greater than one week, exhibiting significant neurological deterioration, PICU admission exceeding ten days, poor prognostic outlook, uncertainty regarding the timing of death, requirement for symptom management (e.g., chronic pain, dyspnea, anorexia/cachexia, intractable nausea, and vomiting), undergoing extracorporeal membrane oxygenation (ECMO), encountering unanticipated treatment complications, and the need for advanced care planning discussion as identified by either parent or healthcare team. The purpose of the RN rounding tool was to provide guidance on patients that would be eligible for screening with the PaPaS scale. RNs were instructed to complete the RN rounding tool daily for each assigned patient and notify providers to complete a PaPaS scale for patients that met the listed criteria.

Table 1: Registered Nurse Pediatric Palliative Care Rounding Tool

PEDIATRIC PALLIATIVE
CARE SCREENING SCALE
(PAPAS SCALE)
RN ROUNDING TOOL

Does your patient have one of the following?:

- | | |
|--------------------------|---|
| <input type="checkbox"/> | Serious illness or life-threatening diagnoses |
| <input type="checkbox"/> | Mechanical ventilation > 1 week |
| <input type="checkbox"/> | Significant neurological deterioration |
| <input type="checkbox"/> | PICU admission > 10 days |
| <input type="checkbox"/> | Poor prognostic outlook |
| <input type="checkbox"/> | Uncertainty regarding the timing of death |
| <input type="checkbox"/> | Symptom management need (e.g., chronic pain, dyspnea, anorexia/cachexia, intractable nausea/vomiting) |
| <input type="checkbox"/> | Undergoing extracorporeal membrane oxygenation (ECMO) |
| <input type="checkbox"/> | Unanticipated treatment complications |
| <input type="checkbox"/> | Need for advanced care planning discussion |
| <input type="checkbox"/> | Identified by either parent or healthcare team member as necessitating PPC |

If your patient has **one or more of the above, please ask a provider to fill out a PaPaS scale**

PPC Referral Tool

The PaPaS scale was developed to promote timely integration of PPC within the disease progression of critically ill children. It uses five main domains (trajectory of disease and impact on daily activities of the child; expected outcome of disease-directed treatment and burden of treatment; symptom and problem burden; preferences of patient, parents, or healthcare

professional; and estimated life expectancy) to generate a cumulative score that aids in categorizing patients and guiding different courses of action (Bergstraesser et al., 2013). A score of 25 or higher supports the need for PPC consultation (Bergstraesser et al., 2013). The PaPaS scale is a widely peer-reviewed PPC screening tool, with a sensitivity of 82.54% and specificity of 100%, and has been applied across various healthcare settings, including the PICU (Chong et al., 2020).

Measures

The main outcome of interest in this project was the number of PPC referrals. This was measured by comparing the number of PPC referrals pre- and post-intervention. The number of PPC referrals will be obtained after the implementation phase of this QI project and was then compared to the number of referrals placed three months prior to the project implementation phase. Additional demographic variables were collected to reflect the age (in years), sex (male, female), and primary diagnosis category at the time of PPC referral (e.g., cardiac, cancer) and PPC referral type (new, established).

Data Collection

Data for this project were collected in paper form and via the electronic medical record (EMR). The PaPaS scales were collected on a weekly basis by the project lead throughout the post-intervention. Data on the primary outcome measure of PPC referrals 3 month pre- and 3 months post-intervention was collected from the EMR with assistance from the UCLA Health Information Technology (HIT) Team. The list of referrals, with corresponding medical record numbers (MRNs), were provided to the project lead.

Analysis

Descriptive statistics (frequencies, percentages, mean, and standard deviation) were used to assess sample characteristics and calculate the percent change in PPC referrals before and after the intervention. A chi-squared test was used to assess relationships between categorical variables (age, sex, and diagnosis), and an independent sample t-test was used to assess group differences (age in years). A p-value of less than or equal to 0.05 was considered statistically significant. All data were analyzed using IBM Statistical Product and Services Solutions (SPSS).

CHAPTER FIVE: RESULTS

Referrals Pre-and Post-Intervention

For the 3-month pre-intervention phase (10/11/2023 – 01/05/2024), a retrospective review of 130 PPC EMR-identified referrals was conducted. After validating each referral by confirming documentation of a PPC consultation note in the EMR and removing duplicates, a total of 11 PCC referrals occurred during the pre-intervention phase. During the 3-month post-intervention phase (02/05/2024 – 03/28/2024), a total of 75 referrals were identified from the EMR. The post-intervention referrals were validated and de-duplicated using the same process used for the pre-intervention referrals, yielding a final total of 16 post-intervention PCC referrals. The percent change between the pre-and post-intervention groups was a 45% increase in total PPC referrals, with a 150% increase in new patient referrals. Unit-based analysis revealed a 43% increase in PICU referrals and a 50% increase in DOU referrals (Table 2). Upon completion of the QI project, a total of 19 PaPaS scales were collected. Of the 19 completed PaPaS scales, 14 scores (15-27) indicated the need to initiate a PPC referral and 5 scores (10-13) represented a need for further assessment.

PPC Patient Referral Characteristics

There was no significant difference between groups related to age and sex. Children in the pre-intervention group were older in mean years compared to the post-intervention group (10 (7.3 SD) vs. 5 (6 SD), $p=0.100$). Males and females were equally distributed between groups ($p=1.00$). There was a statistically significant difference in primary medical diagnosis between groups, with the pre-intervention group having diagnoses that involved the brain (45.5%), cancer (27.3%), and heart (18.2%), whereas diagnoses in the post-intervention group included cardiac (33.3%), hepatic (18.8%), and syndromes / chronic medical conditions (18.8%) ($p=.040$) (Table 2).

Table 2: *Sample Characteristics and Referral Patterns*

Data Collection	10/11/23 – 1/5/24 Pre (n=11)	2/5/24 – 3/28/24 Post (n=16)	
Variables	n (%) or Mean (SD)		p-value or % change
Referral Types			
New	6 (45.5%)	15 (93.8%)	150%
Established	5 (54.5%)	1 (6.3%)	-80%
Total	11 (100%)	16 (100%)	45%
Referral Unit			
PICU	7 (63.6%)	10 (62.5%)	43%
DOU	4 (36.4%)	6 (37.5%)	50%
Child Age			.129
< 12 months	2 (18.2%)	5 (31.3%)	
1-5 years	2 (18.2%)	7 (43.8%)	
> 5 years	7 (63.6%)	4 (25%)	
Mean age, years	10 [7.3]	5 [6]	0.100
Child Sex			1.00
Female	6 (45.5%)	8 (50%)	
Male	5 (54.5%)	8 (50%)	
Referral Dx			.040*
Brain	5 (45.5%)	0	
Cancer	3 (27.3%)	1 (6.3%)	
Cardiac	2 (18.2%)	5 (31.3%)	
Cystic Fibrosis	0	1 (6.3%)	
Liver	0	3 (18.8%)	
Prematurity	0	2 (12.5%)	
Spinal Cord Injury	0	1 (6.3%)	
Syndrome	1 (9.1%)	3 (18.8%)	

* $p<0.05$; T-test used for continuous variables and Chi-square used for categorical variables

CHAPTER SIX: DISCUSSION

Findings from this QI project showed an increase in PPC referrals after a staff educational intervention, which included instructions on using the PaPaS scale to assist in identifying eligible patients. Similar increases in PPC referrals were seen in other studies that utilized an educational intervention. Lafond et al. (2022) found a 33% increase in overall PPC referrals in a 323-bed acute care children's hospital. This study was implemented over a total of four years and the educational intervention consisted of a year-long educational program featuring didactic sessions, mentoring, and QI projects. Newton & Sebbens (2020) found a 300% increase in PICU PPC referrals two months post-intervention after implementing a 15-minute educational intervention, incorporating referral guidelines from the American Academy of Pediatrics (AAP) and National Hospice and Palliative Care Organization (NHPCO), and reinforcing institutional policies surrounding PPC.

However, the use of the PaPaS scale and the RN rounding tool was limited despite interdisciplinary reminders throughout the 3-month study collection period. Only a few studies that used a RN screening tool or the PaPaS scale showed better compliance in RN staff or provider use compared to our project (Shaw et al., 2018; Lutmer, 2016), and many of them evaluated the number of patients meeting the diagnostic criteria for a PPC referral rather than did impact on referral rates. Two studies that used a screening tool showed conflicting findings of 11% (Shaw et al., 2018) and 70% (Lutmer, 2016) in meeting diagnostic criteria for PPC consultation.

Although a limited number of PaPaS scales were completed, 70% of the completed scales recommended preparation for or initiation of a PPC consult. However, it is uncertain if these completed PaPaS scales resulted in a PPC referral as this data was not linked in the EMR. The

low completion rate of the PaPaS scales may be attributed to poor dissemination of project details to all members of the PICU team (e.g., physicians, nurses, nurse practitioners) and some providers (e.g., physicians) with limited time in the PICU, could have decreased enthusiasm or investment in the project, or might be less familiar with the patients in order to complete the scales. An example is domain 4.1 of the PaPaS scale, entitled “Preferences/needs of patients and parents”, which evaluates the patient’s or parents' desire to receive PPC or “formulate needs that are best met by palliative care” (Bergstraesser et al., 2013). To obtain domain 4.1, the parents need to be present and could hinder the provider in completing the PaPaS scale. For example, if parents are absent or working night shift this could hinder the provider in completion of the PaPaS scale. The lack of use of the screening scale in our project may also reflect increased workload and priority in its use during daily rounds. A potential solution could involve utilizing the PaPaS scale as a template in the EMR during rounding with a stop-gap for completion of the provider note or completion after family meetings with the medical team. Another solution would be modifying this screening tool by shortening it. This would allow for improved ease of use in the ICU setting while still promoting early identification. Despite the limited use of the PaPaS scale, there was an increase in overall and new patient referrals, suggesting that an educational intervention may have heightened healthcare providers’ awareness and comfort in initiating PPC referrals. Thereby, potentially facilitating earlier integration of palliative care services.

Unit-specific changes in referral patterns were noted post-intervention, with the DOU having a slightly higher referral rate than the PICU. This may reflect the trend in PPC referrals from non-ICU settings as more of an adjunct therapy in chronic disease management to facilitate improvement in symptoms or quality of life as compared to ICU settings in which providers tend

to consult with PPC in complex or difficult cases (Richards et al., 2018). Further longitudinal exploration is needed to examine practice trends and referral patterns to optimize patient and institutional resources.

The mean age of patients during pre-implementation was 10 years compared to 5 years post-implementation. While age in this project was not statistically significant, there was evidence that younger patients received PPC in the post-intervention group versus the pre-intervention group. This trend may be coincidental, reflect the educational intervention's impact on increased awareness of PPC services, or represent increased provider comfort in referring to PPC. Nonetheless, this demonstrates improved advocacy for PPC services being implemented earlier in the patient's disease course, which has been linked to various improved outcomes (Friedrichsdorf et al. 2019).

Primary patient diagnoses associated with PPC referral revealed statistically significant variation between the pre- and post-intervention groups. Referrals related to the brain and cancer were common in the pre-intervention phase, whereas conditions involving the heart, cystic fibrosis, liver disease, prematurity, spinal cord injury, and syndromes were common in the post-intervention phase. This finding may also be coincidental, or the interventions may have influenced healthcare providers' decision-making regarding the types of diagnoses or conditions deemed appropriate for PPC referral and not reflect solely end-of-life referrals.

In summary, results suggest that despite a small amount of completed PaPaS scales, there was still an increase in total PPC referrals, notably with new patient referrals and shifts in unit-based referrals. While the age and sex of the child did not significantly impact referral rates, type of diagnosis was statistically significant. Our findings complement the existing literature by reaffirming the effectiveness of educational interventions, use of screening tools, with enhancing

the early integration of PPC services (Lafond et al., 2022; Lutmer et al., 2016; Newton & Sebbens, 2020; Shaw et al. 2018). Additionally, these findings highlight the multifaceted nature of integrating the PPC team into the PICU setting, which may benefit from further refinement of screening processes and ongoing educational efforts to enhance the integration of PPC services.

Limitations

Limitations of this project included a single-site setting, short time frame, a small sample size, and threats to validity which can impact the generalizability of the findings (Melnyk & Morrison-Beedy, 2018). The short duration of the QI project may explain the small sample size, limiting the ability to detect group differences. The pre-post intervention design of this QI project may encounter validity concerns such as the likelihood of secular trends or abrupt shifts, which could hinder attributing the observed changes solely to the intervention. However, this threat to validity was minimized because the pre- and post-intervention periods occurred consecutively and in the same setting. Additionally, increased PPC referrals could be related to the Hawthorne effect, which refers to the improvement in performance or behavior of individuals participating in research because they are being observed (Berkhout et al., 2022). Given that the project lead was present in the PICU to encourage participation and pick up completed PaPaS scales, it is possible that the MD and NP participants may have been influenced to engage with the project. Data were not collected on who received the educational intervention and who completed the PaPaS scales (e.g. physicians or NPs), thus limiting our knowledge on who to specifically target for future educational remediation to improve compliance. Lastly, the project lead was not an employee of the institution in which the QI project was implemented, which may have affected buy-in and compliance from key stakeholders and participants of this project. The project lead experienced challenges in understanding unit workflow, ongoing unit workload

challenges, securing project champions within the PICU to help promote the project, and identifying appropriate providers to complete PaPaS scales. This was likely a major factor in implementing the project.

CONCLUSION

The findings of this QI project underscore the importance of early integration of PPC in PICUs to enhance patient outcomes and quality of life. Despite known benefits and professional recommendations, underutilization, and delayed referrals to PPC persist in clinical practice. Implementing an educational intervention and a PPC screening tool resulted in a 45% increase in PPC referrals post-intervention. However, the limited use of the screening tool indicates room for improvement in integration into daily practice. Ongoing educational efforts and systematic approaches are crucial to maintaining early PPC referrals, especially considering the workload challenges in PICUs. Further research and continuous QI initiatives are warranted to optimize the integration of PPC and improve care experiences for terminally ill children and their families.

APPENDICES

Appendix A

Lewin's Change Theory



Lewins Change Model Templates. (n.d.).

Appendix B

B **Bergsträsser Eva** Tue, Aug 1, 6:29AM (5 days ago) ☆ ↶ ⋮

to me, richard.hain@southwales.ac.uk, joseluispereira@hotmail.com ▾

Dear Marché

Thank you very much for your kind email and your request!

It is great to read that you are interested in the PaPaS Scale. I happy to provide you the permission to use the PaPaS Scale for your project. I would be very happy to hear/read about your findings and suggestions for further modifications.

We are currently on the way to do a further validation of the instrument within a prospective study (SPhAERA) where we could recently start the analysis of our data.
Zimmermann, K., et al. (2022). "Specialised Paediatric Palliative CaRe: Assessing family, healthcare professionals and health system outcomes in a multi-site context of various care settings: SPhAERA study protocol." *BMC Palliat Care* **21**(1): 188.

If you have further questions, please do not hesitate to get in contact with me.

Kind regards and best wishes
Eva

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Appendix C

Pediatric Palliative Screening (PaPaS) Scale

Domain and Item Numbers	Item	Characteristic	Score
Domain 1	Trajectory of disease and impact on daily activities of the child		
1.1	Trajectory of disease and impact on daily activities of the child (in comparison with the child's own baseline) (with reference to the last 4 weeks)	Stable	0 <input type="checkbox"/>
		Slowly deteriorating without impact on daily activities.	1 <input type="checkbox"/>
		Instable with impact on and restriction of daily activities.	2 <input type="checkbox"/>
		Significant deterioration with severe restriction of daily activities.	4 <input type="checkbox"/>
1.2	Increase of hospital admissions (> 50% within 3 months, compared to previous periods)	No	0 <input type="checkbox"/>
		Yes	3 <input type="checkbox"/>
Domain 2	Expected outcome of treatment directed at the disease and burden of treatment		
2.1	Treatment directed at the disease (does not mean treatment of disease related complications, such as pain, dyspnoea or fatigue)	...is curative.	0 <input type="checkbox"/>
		...controls disease and prolongs life with good quality of life.	1 <input type="checkbox"/>
		...does not cure or control but has a positive effect on quality of life.	2 <input type="checkbox"/>
		...does not control and has no effect on quality of life.	4 <input type="checkbox"/>
2.2	Burden of treatment (Burden means side effects of treatment and additional burdens such as stay in hospital in the patient's or family's view)	No or minimal burden or no treatment is envisioned.	0 <input type="checkbox"/>
		Low level of burden	1 <input type="checkbox"/>
		Medium level of burden	2 <input type="checkbox"/>
		High level of burden	4 <input type="checkbox"/>
Domain 3	Symptom and problem burden		
3.1	Symptom intensity or difficulty of symptom control (during the last 4 weeks)	Patient is asymptomatic	0 <input type="checkbox"/>
		Symptom(s) are mild and easy to control	1 <input type="checkbox"/>
		Any symptom is moderate And controllable	2 <input type="checkbox"/>
		Any symptom is severe or difficult to control (unplanned hospitalisation or outpatient visits, symptom crises)	4 <input type="checkbox"/>

3.2	Psychological distress of patient related to symptoms	Absent	0 <input type="checkbox"/>
		Mild	1 <input type="checkbox"/>
		Moderate	2 <input type="checkbox"/>
		Significant	4 <input type="checkbox"/>
3.3	Psychological distress of parents or family related to symptoms and suffering of the child	Absent	0 <input type="checkbox"/>
		Mild	1 <input type="checkbox"/>
		Moderate	2 <input type="checkbox"/>
		Significant	4 <input type="checkbox"/>
Domain 4	Preferences /needs of patient or parents Preferences of health professional		
4.1	Patient/parents wish to receive palliative care or formulate needs which are best met by palliative care.	No	0 <input type="checkbox"/> please answer 4.2
		Yes	4 <input type="checkbox"/> do not answer 4.2
4.2	You/your team feel that this patient would benefit from palliative care.	No	0 <input type="checkbox"/>
		Yes	4 <input type="checkbox"/>
Domain 5	Estimated life expectancy		
5.1	Estimated life expectancy	Several years	0 <input type="checkbox"/> please answer 5.2
		Months to 1-2 years	1 <input type="checkbox"/> please answer 5.2
		Weeks to months	3 <input type="checkbox"/> do not answer 5.2
		Days to weeks	4 <input type="checkbox"/> do not answer 5.2
5.2	“Would you be surprised if this child would suddenly die in 6 months time?”	Yes	0 <input type="checkbox"/>
		No	2 <input type="checkbox"/>
		Total score:	

Paediatric Palliative Screening Scale PaPaS Scale

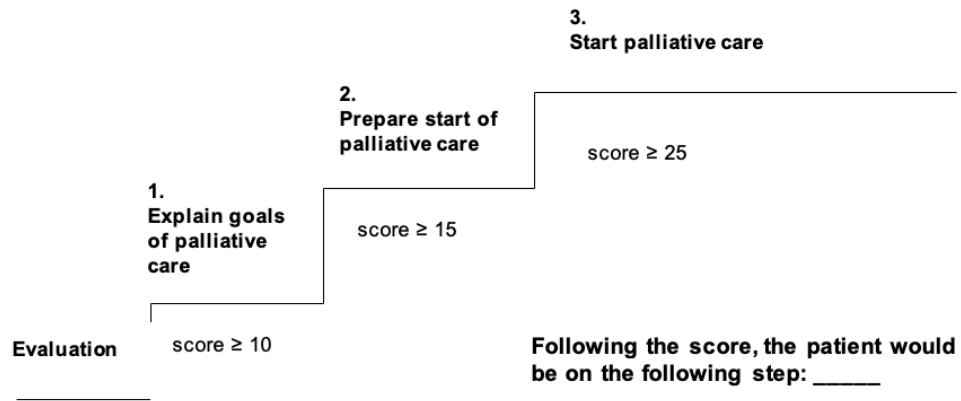


TABLE OF EVIDENCE

Author, Year	Purpose	Sample & Setting	Methods Design Interventions Measures	Results	Discussion, Interpretation Limitation of Findings
<p>Bergstraesser, E., Hain, R. D., & Pereira, J. L. (2013). The development of an instrument that can identify children with palliative care needs: The paediatric palliative screening scale (papas scale): A qualitative study approach. <i>BMC Palliative Care</i>, 12(1). https://doi.org/10.1186/1472-684x-12-20</p>	<p>Aim: develop a screening instrument for pediatricians to improve timely identification of children who could benefit from PPC</p>	<p>Part 1 participants: seven international pediatric palliative care experts from UK, France, USA and Canada Part 2 participants: 11 pediatric health professionals from university Children's Hospital, Zurich</p> <p><u>Setting:</u> Part one: Unspecified Part two: Zurich, Switzerland</p>	<p>Design: qualitative study</p> <p>Procedures Part 1: In-person, semi-structured interviews of seven international PPC experts. Part 2: focus group discussion involving 11 psychiatric health professionals from university Children's Hospital.</p> <p>Methods: 1. Develop conceptual model of published evidence/ authors' experiences. 2. Describe items from focus group specializing palliative care. 3. Preliminary testing for face and content validity.</p>	<p>Five domains relevant to identifying children with life-limiting diseases, who benefit from palliative care: 1) trajectory of disease and impact on daily activities of the child; 2) expected outcome of disease-directed treatment and burden of treatment; 3) symptom/problem burden; 4) preferences of patient, parents or healthcare professional; and 5) estimated life expectancy. Content validity describes chosen items of an instrument are representative for the concept of the instrument. The opinions of experts are used to evaluate face and content validity in an early stage of instrument development.</p>	<p>Findings: early validity evaluated as being a valuable approach towards effective paediatric palliative care</p> <p>Phase 1: uncertainty of use the instrument and further consequences</p> <p>Limitations: The interviewer was also the person who developed the model and analyzed the data, thereby potentially introducing bias. The focus group included only clinicians from a German-speaking Swiss hospital, which affects the generalizability of the results.</p>

					The perspective of affected families, particularly parents, has not been incorporated.
Cuviello, A., Raisanen, J. C., Donohue, P. K., Wiener, L., & Boss, R. D. (2021). Initiating palliative care referrals in pediatric oncology. <i>Journal of Pain and Symptom Management</i> , 61(1), 81–89.e1. https://doi.org/10.1016/j.jpainsymman.2020.07.008	Aim: describe patient characteristics used by oncologists for PC referral and identify ways to improve PC integration into care of pediatric oncology patients.	Sample: 77 participants comprised of 30 attending physicians, 21 pediatric oncology nurses, 18 clinical hematology/oncology fellows, 5 nurse practitioners and 2 child life specialists. Setting: two major academic institutions	Design: Qualitative study Procedures: Recruited pediatric oncology providers via e-mail. IRB approval obtained at both sites. Semi structured qualitative interviews conducted during three months. Discussions focused on PC integration and pediatric oncology. Participants asked to estimate how many of their pediatric oncology patients received PPC consultation and the timing of PPC consultation. Asked what patient/family or disease characteristics trigger them to consult with PPC. Participants given six clinical case scenarios, in which predetermined high-yield triggers based on literature review. Measures: Interviews conducted by the same study member. Recorded interviews were professionally transcribed. Descriptive analysis used	77 interviews completed from oncology team members. 50% of patients were estimated to have received care from PPC team. 75% of participants who requested PPC consult, felt that the timing of consult was too late. 29% of those responsible for initiating PC consult was based on team decision, 27% was based on patient's primary nurse, 25% was initiated from fellow physician, 23% were initiated by attending physician and 15% unsure and 9% of participants reported themselves as the one to initiate PC consult. 98% of participants expressed need for improving PPC integration into care of pediatric oncology patients. Three main themes for achieving PC integration were found from qualitative data: improving communication, providing education, and overcoming system barriers.	Discussion: Few pediatric oncology patients receive PPC services. PPC often received in the late stage of their disease course. Team or nurses often are primary initiator for PPC consultation. Improving formalized PPC education and creating a trigger-based screening tool may improve early identifications of patients who may benefit from PC consult. Additional PPC education may reinforce pediatric oncologists' recognition of PC triggers. Limitations: Results may not apply to other pediatric oncology settings with fewer resources or

			<p>for quantitative interview data, including rates of PPC consult.</p> <p>Conventional content analysis applied to qualitative data, systematically coding and classifying participant responses into common themes.</p> <p>Authors individually assigned codes to a subset of participant responses and met to review and collaboratively grouped codes into called families. Similar code families then combined into themes. Discrepancies among reviewers resolved with repeated discussion.</p>		<p>subspecialty teams available.</p> <p>Interviews were conducted by one study member who was a pediatric oncology trainee, allowing for possible biased responses. Some variability and responses may be reflective of institutional influences for PC consult or limited perspective by interviewees.</p>
Lutmer et al., 2016	<p>Aim: Test the ability of PPC screening criteria to improve access to PPC services in the PICU and examine the association between PPC team involvement and ICU and hospital length of stay.</p>	<p>Sample: 100 patients whom were admitted to the PICU and met criteria for palliative care referral over a 9-month period.</p> <p>Setting: PICU at Nationwide Children's Hospital. a quaternary</p>	<p>Design: Prospective interventional quality improvement study.</p> <p>Methods: Consensus, unit-specific palliative care consultation criteria were created by pediatric critical care medicine and PPC providers. All Patients admitted to the PICU during the 9-month study period were screened for PC eligibility.</p>	<p>Results: 100 patients found to be eligible for PPC services; Referrals were made for 70 patients (70%). PPC consults completed for all referrals. Patients with existing PPC relationship were more likely to still be alive and to have limitations of medical interventions in place.</p> <p>Patients who did not have a PPC referral were more likely to be deceased and to have died in the PICU.</p>	<p>Discussion: PPC screening criteria have improved access to PPC services. The rate of PPC referral increased and embedded in the routine of the PICU attending providers</p> <p>Interpretations: PPC screening criteria are effective tools for improving access to PPC services in the PICU.</p>

		academic medical center; USA		Patients new to the PPC team experienced greater delay in PPC referral and had significantly longer PICU and hospital length of stay than those already known to the PPC team.	Widespread adoption may increase PPC demand. Limitations: Single-center study, small sample size. Lack of patient and staff-centered outcome measures. Limited information on attending provider practice influencing referral rates.
Shaw et al., 2018	Aim: assess the gaps in RN symptom assessment of pediatric patients with life-limiting and life-threatening illnesses and to create a centralized pediatric symptom inventory that could be used between bedside RNs and PPC	60-bed pediatric acute care unit of an academic level 4 trauma center in Charlottesville, Virginia. Participants: 53 patients were identified as meeting the diagnostic criteria during the 4-week pilot.	Design: quality improvement project Methods: The PPC Screening instrument created by using standards of practice for PPC and Hospice and Institute of Medicine report, called “when children die” and chart review from pediatric patients completed in 2016. Initial in-service to teach acute care pediatric RNs the purpose of PPC and how to use instrument. Four-week paper pilot of instrument instituted. The investigator would have RN fill out instrument on each of their assigned patients. Measure:	26 of the 53 patients were identified as having one or more uncontrolled symptoms. 27 had nurse concern. 29 had patient/family concern. Out of 53 patients identified, six had PPC consultation.	Findings: Instrument selective in identifying patients with excessive symptom burden. Implementation of this instrument would not overwhelm PPC team with unnecessary referrals. Instrument selectively differentiates children in need of symptoms support regardless of diagnosis. Nurse, patient and family concern varied by diagnostic criteria. Limitations: Single-center, small sample size, and interrater reliability.

			Measurements collected on 13 separate days during four week. 13 days were determined by random selection by research team members. Descriptive statistics including frequency tables, cross tabulations and chi square analysis		As nurses filled out the instrument according to their subjective opinions, it is unclear whether 2 separate registered nurses would fill out the same symptoms for the same patient.
(Lafond et al., 2022)	Aim: enhance primary PPC skills and confidence among frontline clinicians caring for seriously ill pediatric patients.	Sample: 220 applicants, 209 participants successfully completed the year-long educational intervention. Setting: 323-bed urban children's hospital in the mid-Atlantic region of the U.S.	Design: descriptive correlational pretest/posttest longitudinal design, 4-year duration Methods: participants completed a year-long educational program. featured didactic sessions, mentoring, and quality improvement projects. Addressed clinicians' perceived barriers, such as limited time for in-depth discussions and inadequate PPC availability. Measures: Data were collected through instruments like the PANDA Cubs Application, Moral Distress Questionnaire-Pediatric, and ANCC Educational Design Evaluations.	Results: indicated substantial improvements, with participants reporting increased comfort in having difficult conversations, enhanced end-of-life care comfort (89.5%), knowledge (94.7%) and skills (100%), improved communication (100%), and improved preparedness to discuss and access PPC resources (100%). Most notably, there was a 33% increase in PPC consults, a 98% increase in integration for high-risk cancer patients, and a 52% increase in total PPC team encounters.	Discussion: demonstrated the potential for education and mentoring to strengthen primary PPC, alleviate moral distress, and increase referrals to specialty PPC. Limitations: Single-center design Attrition, drop-out rates
Newton, K., & Sebbens, D. (2020). The impact of provider education on pediatric palliative care	Aim: Investigate the impact of educational	Sample: 64 participants from various departments,	Design: pre/post design, interventional quality improvement study	90.5% (n=58) answered question one correctly, 98.4% (n=63) answered question two correctly, 70.3% (n = 45) answered	Findings: Participants displayed strong comprehension of the

<p>referral. <i>Journal of Pediatric Health Care</i>, 34(2), 99–108. https://doi.org/10.1016/j.pedhc.2019.07.007</p>	<p>sessions and established guidelines on PPC referrals for children managing life-limiting illnesses.</p> <p>To assess knowledge after the presentation, Results showed that</p> <p>Overall, In the post-survey, indicating that they found the information valuable to their personal practice.</p>	<p>including neonatal intensive care unit NICU, PICU, and Center for Cancer and Blood Disorders (CCBD).</p> <p>Setting: A single-center project conducted in a large pediatric hospital in Dallas, Texas,</p>	<p>Methods: Educational sessions were designed based on information processing theory, incorporating referral guidelines from the AAP and National Hospice and Palliative Care Organization (NHPCO), along with institutional policies. The authors and PPC department stakeholders designed pre- and post-surveys for the study.</p> <p>Measures: The pre-survey gathered demographic data, comfortability with palliative care referral on a 6-point Likert scale, and the number of personal PPC referrals placed within the last year. Participants were given four questions related to the presented material.</p>	<p>question three correctly, and 85.9% (n = 55) answered question four correctly.</p> <p>55 participants ranked the value of the information received about PC on a Likert scale from 0 to 5, with a mean score of 4.65 [standard deviation (SD) 0.552], 54 participants ranked their likelihood of making a referral to PPC based on the information provided, with a mean score of 4.52 [SD 0.666]. Hospital-wide referrals increased from a monthly average of 13.5 to 22.0 [SD 2.121 and 5.657].</p>	<p>organization's recommendations and guidelines, Participants more likely to refer to PPC after the educational intervention. Educational interventions can impact PPC referrals and provider comfortability with PPC.</p> <p>Limitations: small sample size, low physician attendance, the format for educational sessions was not convenient for the majority of providers, short time frame for data collection, certain demographic variables were not included on the presurvey.</p>
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