

Pediatric Palliative Care: Identification of the Referral Process and Collaboration of the Pediatric Palliative Care Team and the Primary Care Provider

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Abstract

Purpose: The Pediatric Palliative Care Research Network (PPCRN) is a network of pediatric palliative care hospital programs in the United States and Canada. The objectives of this study were 1.) To determine the referral process to Pediatric Palliative Care (PPC) programs identified in the United States and Canada and 2.) To identify the role of the primary care provider collaboration within the PPCRN. This information was then used to develop a patient education tool for the pediatric primary care provider within the community. The tool could initiate an early referral to PPC, increase access to these services, and improve the quality of life for these children and their families.

Methods: Surveys were sent via email to the 9 PPCRN programs to evaluate the referral processes and the role of the primary care provider within their respective PPC programs.

Results: 5 out of the 9 PPCRN programs responded to the survey. Only 2 PPCRN programs identified collaboration with the primary care provider at initial referral and offered a continued multidisciplinary approach throughout the course of the child's illness. The majority of referrals occur at end-of-life and/or non-curative stage of disease.

Conclusion: Further research needs to be conducted to recognize the barriers of referral at diagnosis despite current guidelines. The possibility of a flagging system for diagnosis criteria should be explored in order to increase identification of children in need of PPC for referral.

Keywords: Pediatrics; Palliative care; Primary care provider

Introduction

Pediatric palliative care (PPC) is defined as the comprehensive care and management of the physical, psychological, emotional and spiritual needs of children and their families with chronic, debilitating, or life-threatening illness [1]. The National Consensus Project (NCP) also defines PPC as a philosophy of care to prevent and relieve suffering and to support the best possible quality of life for patients and their families regardless of stage of disease [2]. The NCP states PPC should be delivered concurrently with life-prolonging care [2]. The NCP's definition of palliative care is consistent with the definition in use by the National Quality Forum and the Centers for Medicare and Medicaid Services [2]. The World Health Organization (WHO) definition of PPC indicates palliative care for children as the active total care of the child's body, mind and spirit that begins when the illness is diagnosed and continues regardless of whether the child receives treatment for the disease [2]. The WHO states PPC should alleviate physical, psychological and social distress through a broad multidisciplinary approach including the family provided in tertiary centers, communities or patient homes [2]. Similarly, the American Academy of Pediatrics (AAP) position statement on PPC recommends "palliative care for children should be integrated at diagnosis and continued throughout the course of the illness, whether the outcome ends in cure or death" [3-6].

AAP, IOM, WHO, NCP recommend PPC begin at diagnosis of a life-threatening or debilitating illness [2,6,7]. NCP lists general criteria for those children that should be included and are listed in (Table 1) [2]. Himelstein [8], identified four categories for conditions that are appropriate for PPC all of which include possibility of death. These categories are (1) conditions where curative or life-prolonging treatment is possible but may fail, (2) conditions requiring long periods of intensive treatment aimed at prolonging quality of life, (3)

progressive conditions where treatment is exclusively palliative from diagnosis, and (4) conditions with severe, non-progressive disability causing extreme vulnerability to health complications. In addition, the NCP has constructed clinical practice guidelines with a policy specific for a PPC referral process [2].

Palliative care for children with life-threatening or chronic illnesses is underutilized in the United States [7]. The survival rate for children with a chronic condition or life-threatening illness has dramatically increased over the past two decades and has demanded a multidisciplinary approach to provide the best optimal care [3,8,9]. Approximately 50,000 children die each year in the United States and roughly 500,000 children cope with life-threatening conditions [3,4,8,10]. Similarly, others estimate close to 2 million children in the United States live with serious medical conditions that could benefit from palliative care [4]. Pediatric palliative care is a philosophy of care that is not about death, but instead encompasses helping children and their families to alleviate pain and suffering and attain the highest quality of life possible. This type of care requires a multidisciplinary approach involving physicians, advanced practice nurses, registered nurses, social workers, psychologists, child life specialists, and spiritual

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Presence of a serious illness and one or more of the following:

- New diagnosis of life-limiting illness for symptom control, patient/family support
- Declining ability to complete activities of daily living
- Weight loss
- Progressive metastatic cancer
- Admission from long-term care facility
- Two or more hospitalizations for the same illness within three months
- Difficult to control physical or emotional symptoms
- Patient, family or physician uncertainty regarding prognosis
- Patient, family or physician uncertainty regarding appropriateness of treatment options
- Patient or family requests futile care
- DNR order uncertainty or conflicts
- Uncertainty or conflicts regarding the use of non-oral feeding/hydration in cognitively impaired, seriously ill, or dying patients
- Limited social support in setting of a serious illness (i.e. no family support, lives alone, homeless, chronic mental illness)
- Patient, family or physician request for information regarding hospice appropriateness
- Patient or family psychological or spiritual distress

Table 1: General Referral Criteria.

leaders. Primary care providers play a large role in recognizing the need for initiating PPC, providing routine health care, assessing and managing pain and distressing symptoms, facilitating advanced care planning, and referring to specialists as needed [3]. Ultimately, PPC should begin at diagnosis of a chronic condition and/or life-threatening illness regardless of curative measures or disease prognosis [2,3,5-8,11,12].

A PPC program is necessary to provide such comprehensive and often times complex specialty services. Many PPC programs exist across the country in children's hospital systems but are either not available to all or are underutilized [7,12]. Subsequently, the referral process for these children to PPC programs is mostly unknown in the research. Thompson found that 38.5% of pediatricians did not have or did not know whether they had palliative care services in their area, and only 49.3% had ever made a referral to PPC. Similarly, Toce and Collins [13], noted more than three fourths of the physicians and nurses found limitations in community availability of PPC services and greater than 50% stated barriers to making a referral to hospice/home care.

Several initiatives are in place to address the needs for palliative care in the pediatric population. One of these organizations is the Pediatric Palliative Care Research Network (PPCRN), which consists of University of Michigan Mott Children's Hospital, Boston Children's Hospital, Seattle Children's Hospital, Akron Children's Hospital, Children's Hospital of Philadelphia, Minnesota Children's Hospital, Children's National Medical Center, University of British Columbia Children's Hospital, and McGill University Hospital of Montreal. This network of hospitals is focused on research to develop the best delivery of pediatric palliative programs.

Despite IOM, WHO, NCP, and AAP recommendations, most providers are unaware of the need to refer a child to PPC at diagnosis of life-threatening and debilitating illness and equate palliative care as similar to hospice and/or end-of-life care consequently making late referrals. In a study by Thompson [7], 41.9% of pediatricians defined palliative care as the same as hospice care. A range of 29.6% - 44.2% of the pediatricians preferred to refer patients to PPC services at the end of life when, only when curative therapy was no longer the goal. Jennings [14], also identified a large gap between supportive care services delivery between the time of diagnosis and the time of end stage illness and hospice where PPC services could be implemented. Pediatric palliative care is underutilized in the United States and is only initiated when curative therapy has ceased and the child enters an end-of-life/hospice program.

Therefore, the purpose of this study is to determine both the referral process to PPC programs and how primary care providers collaborate within the PPCRN. This information was used to develop a patient education tool for the pediatric primary care provider within the community. Ultimately, this tool can increase early referral to PPC, access to services, and the quality of life for these children and their families.

Literature Review

A recent review of the literature found that several different approaches to providing PPC programs within hospital-based systems exist in the United States. Three different models are currently used. These include a full service PPC program, a consultation service, and a staff support and training model [9]. The full service PPC program includes an interdisciplinary team providing inpatient and outpatient consultation, dedicated beds, and home care to patients. A consultation service model of PPC includes an interdisciplinary team staffed from multiple departments or divisions within the hospital system and emphasizes on family meetings. The PPC model existing as a staff support and training program provides in-service training and guidance to front line pediatric staff but does not provide direct patient care services [9].

The referral process differs depending upon which model of service is used. Primary care physicians were found in majority responsible for initiating the PPC referral [10,13,14]. Only one PPC program identified an order was required by the primary care physician to begin palliative care services [10]. In a few cases, the referral process begins with a consult requested by anyone involved in the care of the child. A physician, nurse practitioner, nurse, social worker, chaplain, or family member can initiate this referral [13,14]. In Florida's model for PPC, a registered nurse is the care coordinator and responsible for identifying potential patients in need of PPC [10]. Knapp et al. [15], stated that nurses are the first to identify potential children to physicians for referral and that outside the U.S. nurses have as much referral authority as physicians in PPC.

Several barriers to PPC implementation have been identified in the literature. Thompson [7] stated the term "palliative care" carries a negative perception compared to "support care" among parents and physicians that may hinder referrals. Other barriers include prognostic uncertainties, discrepancies in treatment goals between staff and family members, or communication between physicians and patients [7]. Many patients who require PPC services do not meet eligibility criteria

for community based programs [3,4,8]. Thompson [7] identified health insurance programs as a barrier due to PPC services being rarely covered causing a selection bias regarding which children are referred. Davies et al. [16], also recognized barriers to PPC as limited financial resources, limited access in rural areas, communication problems, false hope for cure, inappropriate continuation of advanced life-saving technology, inappropriate eligibility criteria, fragmented care, inadequate assessment and management of symptoms, lack of research on PPC, and lack of training and expertise. In the study by Davies et al. [16], the barriers most frequently reported among pediatric health care providers were 55% uncertain diagnosis, 51% family not ready to acknowledge incurable condition, 47% language barriers, and 47% time constraints. Miscommunication can lead to increased frequency of resource utilization and poorer patient outcomes [3,8].

Once the referral is initiated, a team of professionals is assembled for the child. The PPC team may include physicians, advanced practice nurses, registered nurses, social workers, psychologists, chaplain/clergy, pharmacists, child life specialists, physical/occupational therapists, and dietitians [3,5,10,14]. Implementation of care among most programs was found to begin with the PPC team performing an initial assessment with recommendations for the plan of care to all providers involved with the child [5,10,14].

Upon PPC implementation, the team updates patient's care plans and follow-up throughout the course of the child's illness collaboratively with the primary care provider [5,10,14]. Jennings [14], specifically noted the primary care provider continues to manage the medical care of the child while the PPC team is available for consultation. The nurse practitioner/certified nurse specialist provides inpatient and outpatient direct care and develops the patient's plan of care [14]. In contrast, Knapp et al. [10], noted the PPC team develops the care plan for the child and a copy is sent to the primary care provider along with updates to facilitate collaboration between medical and palliative care.

The coordination of care was found in the literature to differ among PPC programs. One PPC consultation program identified the nurse practitioner or certified nurse specialist as the care coordinator to collaborate with other team members [14]. Similarly, another PPC program designates a registered nurse as the care coordinator to collaborate services for all of their children in need [15]. However, one PPC program specifically identified a hospital-based "continuity physician" as the care coordinator during all hospitalizations and in the community in order to collaborate care across all sites of treatment [13].

In order to address the barriers of PPC service implementation and facilitate collaboration, the AAP offers a model for a multidisciplinary approach such as a medical home to establish coordination of care. The AAP [17], policy statement indicates children with chronic illnesses receive access to coordinated, comprehensive, continuous, compassionate, culturally effective, and family centered care within a medical home provided by the care coordinator. This coordinated care is dynamic and multifaceted to identify, assess, prioritize, and monitor all aspects of care for a variety of services including community-based preventative care, specialty services, educational and community organizations [17]. Ultimately, the medical home represents a unique shift in care provided for children with chronic life-limiting illnesses to utilize a comprehensive model that encompasses the child and family, the PPC team, and the primary care provider. A multidisciplinary approach is necessary to facilitate communication, increase early referral to PPC services, and overall quality of life.

Only one existing program in the literature specifically stated their

objective to begin PPC referrals at diagnosis of chronic and/or life-threatening illness. Knapp et al. [10], defined Florida's PPC model as the first publicly funded program from the point of diagnosis onward where PPC is integrated with curative therapies for these children. At the program's inception in 2006, the number of enrollees totaled 80 children where only 5% were newly diagnosed, 75% mid-stage of diagnosis, and 20% at end-of-life [10]. The study described a non-biased tool developed and implemented to address inconsistencies in potential patient identification strategies. The tool uses a list of eight diagnoses and their codes to flag Medicaid or the state's insurance plan applications to increase enrollment. Once the identification tool was implemented along with other strategies such as development of relationships with local children's hospitals and community programs; the enrollment dramatically increased in two years. In 2008, the PPC program had increased enrollment to 468 children with 7% newly diagnosed, 85% at mid-stage of diagnosis, and down to 8% for children at end-of-life [10].

Methods

Study design

A qualitative approach with a survey composed of 7 open-ended questions was sent to the PPCRN to evaluate the referral processes and the role of the primary care provider within their respective PPC programs. The surveys were administered via email to the nine directors of the PPCRN programs.

Survey

The survey was developed based on the review of PPC literature, the IOM, NCP, WHO, and AAP guidelines, and personal bedside nursing experience while caring for children with chronic life-limiting illnesses and their families (Appendix A). The questions were directed to identify the key points in the referral process along with primary care provider collaboration.

Sample

The PPCRN is a research network of pediatric palliative care hospital programs in the United States and Canada. There are nine member hospitals included: Boston Children's Hospital, Akron Children's Hospital, Children's Hospital of Philadelphia, Seattle Children's Hospital, University of British Columbia Children's Hospital, Children's Hospital of Minnesota, Children's National Medical Center DC, McGill University Hospital Montreal, and University of Michigan Mott Children's Hospital. Most hospitals are located within major metropolitan areas providing inpatient, outpatient and tertiary care for children from infancy to approximately 21 years of age.

Results

All nine PPCRN programs were contacted a minimum of two times via email. No incentive was offered for survey completion. Five out of nine PPCRN programs responded to the survey questions, four did not respond and offered no stated reason for declining participation in the survey.

Referrals

When do you initially get a referral to palliative care? (Diagnosis, Non-Curative, or End-of Life) Two programs stated specifically that initial referrals were completed at non-curative and end-of-life. Another two programs identified most of their referrals are for chronic life-threatening illness and not end-of-life care. One program reported actual referrals consisted of 30% care coordination, 23% family support,

21% pain and symptom management and 20% end-of-life planning. Another program responded that of their referrals, 65% were during chronic illness, 30% near end-of-life and 5% at diagnosis. One program reported referrals vary but are often for symptom management or goals of care including end-of-life care.

Who can refer to palliative care? Is there an order, and if so who must sign the order? Most of the PPCRN programs allow anyone within the multidisciplinary team as well as family members to initiate referral. One program reported that palliative care clinicians and oncologists initiate referrals. In response to whether a signed order is required, three programs reported a necessary physician order to begin PPC. However, a physician order is not required for the remaining two programs.

What are the criteria for a referral to the palliative care program? Are there any other factors considered? One program's criteria include symptom management, anticipatory guidance, goals of care, patient/family support, end-of-life plans, and "in times of uncertainty". Another program stated criteria involves any child with chronic, complex, or life-threatening illness or medically fragile. This same program also identified trigger categories for referral including 1) new diagnosis of complex congenital heart disease 2) bone marrow transplant admission 3) intensive care unit admission greater than one week 4) technology-dependent 5) muscular dystrophy 6) in utero diagnosis of severe anomaly 7) patient controlled analgesia need, and 8) renal failure as a non-transplant candidate. One program identified referral criteria as any child with a diagnosis, usually chronic, that affects quality of life or is considered "life-limiting" receives PPC referral. Two programs did not report specific referral criteria to PPC services. One program stated "troubling symptoms, end-of-life, and difficult medical decisions" as other factors considered for PPC referral.

Time from referral to implementation

How long is the process to initiate palliative care consultation? If delayed, do you think it's based on perceptions of palliative care in general or other factors? All five programs reported the ability to see a patient/family within 24 hours usually the same day of the referral. Three of the programs stated urgent requests are triaged to prioritize consults for symptom distress. Additionally, one program identified most referral time frames are short and depend on the subspecialty to be immediate or up to several days.

However, different results were reported on the delays of PPC implementation within the PPCRN. The delays were based on misconceptions partly because of "just not thinking about it" for one program. Another program identified delays in referral due to provider's unfamiliarity with the service and fear of "offending" the family of the child. Two programs found delays in implementation due to PPC being synonymous to end-of-life care. One program noted family reluctance as a delay in referral process to PPC.

Collaboration with the primary care provider

Does the primary care provider become involved in this process? Two programs reported direct involvement with the primary care provider in the referral process. However, one of these two programs identified the specialist as the primary care provider. Two programs responded that involvement with the primary care provider "depends" without any other explanation. Subsequently, one program did not respond to the primary care provider's involvement.

Once the initial consultation is complete, is there discussion between the palliative care team member and the primary care provider to

determine the role of the palliative care team? All five PPCRN programs identified discussion between the PPC team and primary care providers exist. One program reported that the PPC team helps negotiate the primary care provider's roles in PPC. Another program stated that collaboration includes transition of care to the primary care provider and continued involvement of the PPC team if the family desires.

In the community setting, does the patient continue coordinated palliative care through a multidisciplinary approach? Or does the primary care provider solely provide care along with separate specialty care visits without palliative care involvement? The majority of the PPCRN programs reported collaboration with the community primary care provider. Three programs reported direct coordinated multidisciplinary care. Of those three programs, one stated that follow up care is continued at the request of the family. Two programs stated a lack of collaboration among the PPC team and the primary care provider, with one of them providing mostly inpatient services. One program identified the PPC team for hospice care or symptom management is often in conjunction with the local home care department.

Discussion

In order to provide the highest quality of life for children with life-threatening or debilitating illnesses and their families, PPC referral must be initiated and provided to these children at time of diagnosis [2,3,6,7,8,12]. Within the PPCRN, only two programs stated referrals were done for children with chronic, life-threatening illnesses. The remaining three programs only initiate referrals for children that have non-curative diseases or require end-of-life care. Palliative care does not equate to end-of-life care [8]. However, only one PPCRN program reported 5% of their referrals occur at diagnosis. Another PPCRN program stated most referrals occur for chronic, life-limiting illnesses and at not at end-of-life, but no mention of whether referrals were made at diagnosis. Despite current guidelines calling for all children to benefit from PPC at diagnosis of illness, the literature and PPCRN surveys found the majority of PPC programs are delayed in implementing services. This finding confirms previous research that has identified barriers to implementing PPC at diagnosis. Many barriers have been identified in the research, but even specialized programs such as those within the PPCRN are not implementing PPC at diagnosis.

Most of the hospitals within the PPCRN are consistent with the current literature in the identification of children requiring PPC services. Any person caring for these children including physicians, nurses, and other hospital staff as well as family members can identify and initiate referral to PPC. Identification of children for PPC services has been researched in the literature and noted as a barrier for PPC implementation not to mention at diagnosis of illness. Even though the NCP has a specific referral process for PPC, not one of the PPCRN programs has similar referral criteria to their own PPC program.

Once the child has been identified as in need of PPC services the referral process can then proceed in several directions. The time frame for implementation was found to be unanimous within the PPCRN programs in that PPC is delivered immediately or within a 24-hour time frame in urgent situations. However, the PPC programs differed in their factors for implementation delays. A general consensus among PPCRN programs found that PPC is delayed as a result of family reluctance and being synonymous with end-of-life care. Consequently, if palliative care is then given urgently or within a quick time frame, was the child specifically already at the non-curative stage of disease and/or end-of-life and denied earlier access to PPC. The focus of PPC should be increasing overall quality of life for children and families through

the course of a complex life-limiting illness and not for the few hours or days before end-of-life care is initiated and/or death unfortunately occurs.

As noted in the literature, one PPC program required a hospital physician's order to begin services. A general understanding exists that most reimbursement agencies require a physician's order to bill for services. Within the PPCRN, 3 of the 5 programs require a physician order to implement PPC. This finding raises the possibility that the need for a physician order may hinder the identification of potential children for PPC services. Further research is needed to determine if this requirement is a barrier in the referral process.

Within the PPCRN, only two programs specifically stated the primary care provider was involved in the palliative care referral process and held a continued multidisciplinary role in implementation of care for that child. This finding is consistent with the literature. With the medical home movement already underway, multidisciplinary collaboration among providers and services is necessary to provide access to consistent, coordinated quality health care to patients and their families. The child's primary care provider whether pediatrician or pediatric nurse practitioner must remain involved in the care of the child and holds a major role in coordination of routine, curative, and palliative care. So many children "slip through the cracks" where one physician believes and/or assumes the other physicians are handling all aspects of care. In fact, necessary services such as symptom management may be unknowingly lost. With the inception of the medical home, the multidisciplinary collaboration among providers offers guidelines and a renewed hope for increased referral and access to PPC services.

Limitations

The limitations of this qualitative survey include Master's student development of the survey questions and use of non-standardized tools. Reliability and validity of the survey was not established and self-reporting measures of the survey responses could be biased. Another limitation is the lack of relevant research available regarding PPC programs. The information collected was from a convenience sample of hospitals. Only 5 out of the 9 PPCRN programs responded to the survey therefore our findings could not be generalized. An additional limitation of this study is lack of resources available to evaluate a larger group of PPC programs.

Clinical Implications

The results of this survey offer several opportunities for improving the initiation of PPC at diagnosis. The NCP has a detailed referral process and specific guidelines that are available through the IOM, WHO, NCP and AAP for quality PPC implementation [1,2,6]. However, these policies and guidelines seem to be underutilized and/or unavailable to PPC programs. Two targeted interventions may improve the initiation of pediatric palliative care services.

First, a standardized set of recommendations could be made available for all professionals working with children and families. A new standard of patient identification for PPC services can be explored such as with Florida's PPC program. The program specifically identifies patients through a "flag" place on eight diagnoses in the state's Medicaid applications [10]. The trigger diagnoses can also be expanded to include the criteria listed in Himmelstein [8]. Additionally, other forms of insurance such as children's special health services and/or private party payers could flag their applications for such trigger diagnoses.

Second, continuing education for primary care providers

could improve their knowledge of appropriate referrals to PPC programs. The use of the medical home philosophy of care may offer further implications for primary care providers to collaborate in a multidisciplinary approach to provide quality PPC. Due to the concern regarding financial reimbursement of services, providers could be educated that children can begin some aspects of PPC such as symptom management. Children should no longer miss an opportunity to benefit from PPC due to a lack of provider knowledge.

The results of this survey and the current literature support the inadequate knowledge of providers in PPC definition, referral and implementation. In the study by Thompson [7], pediatricians still define palliative care as similar to hospice thus making late referrals and stressed a need for further education. Palliative care needs to be recognized as supportive care to remove the stigma of solely end-of-life/hospice care. The change in terms to supportive care alone would increase referrals for these children. Primary care providers are on the front line to identify and implement PPC to their patients and can be given the tools necessary to do so. As a result of the literature reviewed and the surveyed results, a patient education tool was created for distribution in the primary care provider's office to increase knowledge, awareness, and ultimately referral to PPC services. The PPC handout includes a concise definition, criteria for referral, links to resources, and summarizes the services that would be provided to the child and family (Appendix B).

Conclusion

Children endure complications due to chronic, life threatening and debilitating diseases at the expense of curative therapy. The successful use of the medical home model and increased provider education may address identified barriers to implementation of palliative care for children. Specific diagnostic criteria for automatic referral may also address current barriers. Further research regarding the referral process to PPC may allow more children to benefit from quality, comprehensive, collaborative PPC programs and to increase their overall quality of life.

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