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REVIEW ARTICLE

Palliative Care in the Pediatric Population

Performance of health professionals and the main interventions in pediatric palliative treatment

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RESUME

This is a proposed literature review to demonstrate the main interventions carried out by healthcare professionals in pediatric palliative care (PPC) based on current studies. It aims to show the methods used in palliative care programs and the results obtained. Methodology: The study searched for articles on PPC and end-of-life (EoL) care in the pediatric population using the CAPES study platform. Twenty articles were found in this selection. Results: With the continuous advancement of oncological treatments, many studies are conducted on the pediatric population, with special attention to palliative care. Many of the issues addressed are not only about the treatment itself but also about understanding the factors involving healthcare professionals, families, and patients. Multidisciplinary work has been extremely relevant to improving the quality of life of pediatric patients, for the development of shared care plans, and for promoting an understanding among both patients and families about palliative treatment. Research shows that patients referred to palliative care undergo fewer invasive interventions than patients who are not referred. Moreover, the psychological aspect of families within palliative care shows a better understanding of the treatment and better acceptance of the prognosis.

Conclusion: Approaches to this treatment are still diverse, and referral methods are still scarce and nonspecific; however, interventions proposed by specialized palliative care groups have proven to be extremely effective.

Introduction

Current pediatric palliative care (PPC)[1],[2] focuses on providing comprehensive support to children with severe illnesses and their families. This approach aims to improve the quality of life for children facing life-limiting conditions by effectively managing symptoms, addressing emotional and psychological needs, and offering family support throughout the disease trajectory[3]. It involves a multidisciplinary team comprising doctors, nurses, social workers, psychologists, child life specialists, and other healthcare professionals who work together to tailor care plans to the specific needs of each child and family[3]. The role of this planning is extremely important as it integrates the best patient management with less invasive interventions, addresses social and family issues by preventing isolation and inefficient communication, and shapes home care for better comfort for the family and patient whenever possible. PPC also emphasizes that it is the whole person, not just the body, that suffers, and that suffering extends beyond the physical domain and can exist even in a person devoid of symptoms[4]. Additionally, pediatric palliative care emphasizes open communication, shared decision-making, and coordination with other healthcare providers to ensure that the child's physical, emotional, and spiritual needs are met.

Specialized pediatric palliative care (SPPC) is an integrative model of care for children and adolescents with poor prognosis diseases, aiming to alleviate suffering, improve the quality of life for the child and family, and support families in general decision-making[5]. Palliative care is essential in universal health coverage, and several studies have shown how the availability of PPC services improves the quality of life for patients and their families[6], and how this treatment model can promote cost reduction in treatment[7,8].

Although there has been an increase in resources devoted to palliative care in recent years, there is little evidence about the pediatric population served, little discussion about care models, the organizational characteristics of these resources, the services provided and their effectiveness, or the level of guidance for shared decision-making with patients and families[9]. In this sense, this study aims to demonstrate how PPC has been carried out in various countries and to highlight the most effective interventions that improve the quality of life for both patients and their families.

Methodology

This article used the CAPES platform to conduct research on the main interventions in pediatric palliative care. A total of 13,303 articles were found using the descriptors 'pediatric palliative care interventions' from March 1, 2024, to March 11, 2024. After applying filters for articles, open access, years 2019-2024, and the English language, 2,657 articles were found. Of these, the first 1,000 articles, ordered by relevance on the platform, were selected to suit this article, with 20 of them being included as they answered the current research question.

For the selection of articles, the criteria were articles that could be fully accessed and that answered the main question of the article: 'What are the main approaches currently used in pediatric palliative care?'. The composition included cohort studies, case-control studies, and cross-sectional studies.

The shortcomings of the studies used are generally related to the lack of patient data and the failures in the justification for referral to the PPC sector. Few studies evaluate the family and the expectations of patients. The evaluations of the type of PPC used are also flawed. Another important issue is that many data are lost during the follow-up of patients due to poor prognosis diseases. Many studies are retrospective and depend on the description in medical records or other sources for information. Professionals in this field are also scarce, and their participation is extremely necessary in most cases. Symptom assessment also appears to be underestimated. Many articles are still merely descriptive, with few official data to demonstrate that the use of PPC is indeed appropriate.

This article aims to understand, based on the current literature, how the therapeutic approach to patients in pediatric palliative care is conducted, and thereby define the best current practices.

Results

A total of 13,303 articles were identified on the CAPES platform using PPC descriptors. After applying filters, 2,657 articles were obtained, of which the first 1,000 articles, ranked by relevance on the platform, were evaluated. Of these, 20 articles were included.

Most of the articles provide an assessment of the PPC methods used in various services, demonstrating the quality and efficiency of PPC methods as well as the need for improvements in each type of service. Some articles compare different types of PPC and evaluate practices in different countries. There are some studies that show the work of professionals with specific interventions, such as those from the fields of physical education and psychology. Invasive interventions and ICU care are reported in some studies, and there is also essential care for the end-of-life (EoL) period, including the use of palliative sedation. Additionally, there are possible interventions within the prenatal period, with increasingly earlier diagnoses and interventions possible even before birth. The results are better reported in the development.

Development

GENERAL PALLIATIVE CARE INTERVENTIONS

A retrospective cohort study[10] conducted at the Louis Dundas Centre for Children's Palliative Care (LDC) at Great Ormond Street Hospital in London, covering London and England from 2007 to 2021, evaluated the specialized multidisciplinary pediatric palliative care (PPC) service for prenatal referrals. It showed that over the years, there was an exponential increase in referrals to this service, from 2 per year in 2007 to 36 referrals per year in 2021. Out of a total of 159 cases, the majority of referrals occurred between 21 and 30 weeks of gestation (47%) and between 30 and 35 weeks (34%). Among these, cardiac comorbidities (29%) and trisomy 18 (28%) were the most common referrals. Of all the patients, 33 died in utero, 15 were stillborn, and 28 died within 24 hours of life. Seventeen died between 24 hours and 1 week of life. Only 30 were alive at the end of this study.

Another retrospective study[11] of medical records conducted at an Italian perinatal center over a period of 4 years (2016-2020) aimed to evaluate the care of fetuses and newborns eligible for perinatal palliative care (PnPC). Forty-five patients were eligible for PnPC, with 27% diagnosed prenatally, 27% preterm at the viability threshold, 35% newborns with life-limiting or potentially fatal diseases diagnosed in utero or in the postnatal ward, and 45% were newborns unresponsive to intensive care interventions with high health care needs or medical complexity. Fifty-seven percent died before discharge, and 35% were discharged home. The median age at death was 4 days postnatal, and 13% died in the delivery room. Of the 21 patients who died, 57% died under maximum support measures and 44% died under primary care; 35% were discharged home.

The patients were divided into groups: Group 1: newborns at the viability threshold (birth weight <500 g or gestational age less than 24 weeks); Group 2: newborns with life-limiting or life-threatening diseases diagnosed in utero or in the postnatal ward; Group 3: newborns unresponsive to intensive care interventions with high health care needs or medical complexity. In Group 1, 22% died in the delivery room, while 77% died in the intensive care unit (NICU). In Group 2, with 26 newborns, of which 2 were stillborn, 25% died in the delivery room, 2 in the NICU, and 8 were discharged from the hospital, with 4 in PPC. Group 3 included 20 neonates, 60% died in the NICU, and 40% were discharged home for PPC. Of these, 75%

were discharged from PPC and followed up only in pediatrics.

The PPC team was involved in 67% of cases, being 50% in 2016 and 88% in 2019. The duration of PPC ranged from 1 to 853 days, with a median of 99 days. For those discharged home, the duration ranged from 18 to 853 days, with a mean of 316 days. In this group of 16 infants, the main issues were neurological symptoms (69%) and dysphagia (81%), with 62% needing naso-orogastric tube insertion, 20% percutaneous endoscopic gastrostomy, and 12% tracheostomy. Additionally, 40% of the patients needed mechanical ventilation at discharge, and one patient had a central venous catheter inserted. Half of the families agreed to ongoing psychological care.

COMMUNICATION AND PSYCHOLOGICAL INTERVENTIONS

An update[12] on PPC was conducted based on the American Society of Clinical Oncology (ASCO) and the need to integrate palliative care into routine pediatric care. It evaluated both the physical factors of the disease and the psychological and familial factors. Among them, it was shown that pain is one of the main symptoms to be managed in this care, being more common in children with solid tumors than in hematologic malignancies. Despite its importance, there are still reports of inadequate pain management from children and families. Besides this symptom, others gain importance, such as dyspnea, nausea, fatigue, anorexia, fever, mouth ulcers, diarrhea, headache, and neuropathy during chemotherapy and palliative phases.

Another important point discussed in this study[12] is the anxiety that children experience about the communication of their comorbidity. When they were not aware of what was causing their symptoms, they felt the need to know what was happening and were able to understand. Little was discussed about the comorbidity, expectations, and ways to cope with death. This generated anxiety and worries in the children. In this context, parents found it difficult to deal with emotional issues, isolation, and changes in their children's behavior. The stressful treatment routine and uncertainties about the future, in addition to financial difficulties, increased negative feelings among parents and children. The perception of parents and children regarding the understanding and experience of the disease created communication barriers between them, leading to treatment abandonment and feelings of neglect by the children for not receiving appropriate treatment. Multidisciplinary support aimed at effective communication between parents, caregivers, and patients facilitates decision-making and improves treatment and symptom outcomes.

After the patients' death, some families regretted providing hospital care instead of PPC during the terminal phase of the disease. Triggers of guilt and sadness were activated during the grieving process, feeling that the treatment did not improve the patients' symptoms at the end of life. Few patients were referred to PPC late, with an average time between diagnosis and referral of 18 months. Only 18% were referred immediately after diagnosis, and the majority, 58%, were referred after cancer recurrence, with most referrals happening only in the last days of life.

The PPC approach in this study[12] helped improve family communication and interaction with the care team. It also allowed for discussions among them and better approaches to end-of-life care, aiding decision-making, discussing future goals, and documenting treatment preferences and invasive or non-invasive approaches, making it possible to plan appropriate interventions. This reduced invasive interventions and resuscitation at the end of life, resulting in fewer and shorter hospitalizations, and more deaths at home. Therefore, PPC referrals allowed cost reduction, treatment continuity, and facilitation of integrative therapies at the end-of-life phase. For the palliative care approach in the study, a 2016 model with three levels of care was used: first, a team for managing complex symptoms and psychosocial care; second, a liaison service for consultations and referrals to palliative care; third, a palliative approach by the entire team with at least basic training in these care.

Another interesting factor in the study[12] is the definition that referrals were not well justified by healthcare professionals, and there were not many reports on how the decision to refer was made. Some present reports demonstrate that the difficulty in treating symptoms, psychosocial needs, and poor prognosis interfered in this decision. Furthermore, end-of-life communication is quite flawed for family and patient understanding, promoting invasive medical interventions at the end of life and increasing hospital deaths. Thus, there is a lack of knowledge among healthcare professionals regarding the assessment of palliative care needs and the use of tools for this assessment, such as the Pediatric Palliative Screening Scale (PaPaS).

Another study[13] evaluated children in PPC and their characteristics, as well as the best interventions and goals of some types of PPC. It highlighted that children with advanced cancer frequently experience symptoms such as chronic pain and fatigue, respiratory problems, nausea and vomiting, cachexia, and nutritional intolerance and constipation. In PPC, the control of these symptoms and chronic pain is done through both pharmacological and non-pharmacological interventions, including physical, behavioral, and cognitive therapies with distraction, attention, imagery, relaxation, and behavioral management techniques combined with appropriate drug dosages. The most common symptoms presented by pediatric patients in the few days before death (EoL) are pain, fatigue, dyspnea, reduced mobility, lack of appetite, cachexia, nausea and vomiting, weakness, difficulty swallowing, anxiety, sadness and depression, and delirium. In EoL, any therapeutic intervention should be balanced between risks and benefits, such as the need for palliative sedation for extreme respiratory distress and interventions with advanced equipment or intrusive procedures like blood transfusions, enemas, tubes, etc., when truly necessary.

Moreover, the relationship between professionals and patients should be well established. In the doctor-patient-family relationship, for example, there is a need for well-developed communication and engagement so that together they can progress towards advanced care planning (ACP). ACP allows patients and doctors to meet and make decisions in the context of collaborative communication, considering scientific evidence and the values, goals, and preferences of patients and families. This planning is essential when done in a timely manner for defining end-of-life care, clarifying desired interventions, treatment discontinuation, symptom management, and the need for resuscitation, as well as the issue of palliative sedation for intolerable and therapy-resistant symptoms. The most commonly used drugs in these cases are benzodiazepines (midazolam in continuous infusion), opioids (fentanyl, morphine), or anesthetics (propofol). Besides EoL treatment, issues of grief and post-death care discussion should also be observed.

Psychological concerns are also prominent in this population, with symptoms of anxiety, sadness, depression, fear, boredom, and behavioral disorders. However, hope and faith are protective factors. Social issues also appear, such as social isolation, shame about social image, and poor social understanding of the disease state. To assist with these difficulties, symptom burden and quality of life assessment scales are used, such as the PROMIS (Pediatric-Reported Outcome Measurement Information System) form, the PEDsQL scale, and the Memorial Symptom Assessment Scale (MSAS). The scales should be selected based on the child's age, cognitive state, and culture. PPC teams need to be aware of the family's level of understanding of the disease and prognosis and adapt communication to be clear for the family members. Clear and efficient communication should be encouraged among patients, their families, and the healthcare team.

This allows everyone to participate in managing treatment preferences and care goals.

The suitability of the PPC model for each type of patient is also mentioned in this article, defining that an existing PPC model uses the early integration of palliative care principles in pediatric oncology as early as the second consultation after diagnosis. At this point, the main treatment issues, future prognosis, and concerns are already established. In some models, a PPC oncologist is added to the main treatment to assist with care and provide greater knowledge to families. However, there are still few specialists in this area. Another possible model integrates the PPC team with the onco-hematology team from diagnosis, directly working on curative and palliative treatment from the beginning for patients who may have multiple physical and emotional problems. This way, it is possible to provide comprehensive treatment to patients.

In this study[14], PPC programs were evaluated in 2018. Fifty-four inpatient programs, representing 29 states and the District of Columbia, submitted data and were identified as a PPC program. The programs were in non-profit (89%), urban (83%), and teaching hospitals (100%), covering 75 to 700 beds, mostly offering services from birth to 25 years of age. The analysis showed that only 20 programs (37%) met the national recommendations for essential team composition, with the missing programs needing chaplaincy (52%) or social work (33%). Only (78%) had physicians certified in palliative care and medicine.

RECURRENCE OF SYMPTOMS

A specialized PPC service in Mumbai[15], India, over a five-year period (2010-2014), used data from 1,135 children with advanced cancer to evaluate their treatment. Referrals were made by the pediatric hematology-oncology team in 28% of the total children, 72% had recurrence or progressive disease being treated by the PPC, 29% received chemotherapy, and 32% had bone metastasis. Scales were used to assess and monitor these patients throughout the research, evaluating intense pain in 20% of patients, loss of well-being in 9%, severe fatigue in 7%, with only drowsiness, shortness of breath, and nausea being less common. Among those over 5 years old, 43% had mild depression and 55% had mild anxiety. Of the referrals, 30% were for counseling and communication purposes, while 21% were for symptom management, 18% for treatment decision support, and 17% were not mentioned. Additionally, symptom evaluation showed 14% had poorly controlled complex symptoms, 10.5% of children were referred back to oncology for palliative radiotherapy for pain and other symptom control, and 17% of patients needed assistance with rehabilitation through occupational therapy. Curative treatment had to be stopped in 25% of cases, and discussions about prognosis occurred in 5.5% of cases. About 90% of patients were cared for at home in their last days of life, and 55% of patients died at home. Telephone support was necessary for 66% of the children and their families by the PPC team.

COMMUNITY-BASED PPC (CBPPC) INTERVENTIONS

A community-based PPC (CBPPC) study[16] involving parents and children with cancer reported that CBPPC treatment improved symptoms and quality of life for the children, enhanced communication, reduced administrative barriers, and decreased caregiver burden and psychological stress. CBPPC services demonstrated an increased percentage of children dying at home according to family wishes. Additionally, there was continuity of care for children and families, better communication between support services, and prevention of unnecessary hospitalizations. This also promoted a reduction in hospital stay duration, emergency service use, and overall hospital costs, along with psychological support, daily living activity support, clarification of important diagnostic and prognostic issues, and assistance with socio-legal matters.

The study[16] also highlighted some key characteristics for initiating PPC treatment: difficult-to-control symptoms; more than three hospitalizations in 6 months; hospitalization for more than three weeks without improvement; ICU stay for more than one week without improvement; need for new medical equipment; complex psychosocial needs; use of more than three subspecialties with communication difficulties between sectors; need for care coordination; need for difficult decision-making; difficulty reaching consensus on treatment between the child, family, and treatment team; difficulty in resuscitation decision-making; ethical issues in palliative care; need for enhanced home care; anticipation of complex conditions; and anticipatory grief. Another issue discussed was the inconsistency between pediatric oncologists who rated pain management as competent and parents reporting their children dying in pain in 50% of cases.

In 2005, Florida created a PPC program called "Partners in Care: Together for Kids," offering home and community services for children and families from diagnosis through the disease and during bereavement. Curative therapies and PPC are subsidized through Medicaid, though this can delay CBPPC. California created the Partners for Children, a CBPPC program also with Medicaid support, under the Nick Snow Hospice and Palliative Care Act. Colorado and Illinois use waivers and similar reimbursement mechanisms to subsidize their CBPPC programs. New York and North Carolina offer similar models but have expanded CBPPC services to include "medically fragile" children to prevent prolonged hospitalizations. Washington State uses a combination of Medicaid programs, private payers, and collaboration with local palliative and home care agencies, integrating CBPPC with curative therapy, offering up to six home PPC visits per month for children in treatment. Massachusetts has funded its model since 2006, supporting PPC physician education and the design and implementation of effective CBPPCs through the Pediatric Palliative Care Network (PPCN). Similarly, the Children's Hospital of Philadelphia's Pediatric Advanced Care Team (CHOP PACT) collaborates with external programs, working with Partners in Pediatric Palliative Care, offering home services and various PPC and home care agencies in five states. CBPPC programs benefit from engagement with broader hospital infrastructure, providing educational, research, and networking opportunities to interdisciplinary providers.

Other programs across the country have proven effective, serving as examples of CBPPC, each developing protocols and improving their treatment skills. These programs also help in the development and design of new CBPPC programs elsewhere, simplifying their incorporation. To promote better organization for patient quality of life, the National Quality Forum published "A Framework for Preferred Practices for Palliative and Hospice Care Quality: A Consensus Report," highlighting 38 practices associated with quality palliative care. This and other programs are featured in the research.

PALLIATIVE CARE PROGRAMS IN DIFFERENT COUNTRIES

This study[17] also provides data on the current structure of pediatric home palliative care services in 33 European countries. The most common services were related to medical professional care (81.0%), nursing care (71.4%), and care coordination (71.4%). In 81 countries with pediatric home palliative care, at least two professions were involved in all national teams. The highest number of multiprofessional teams was in the Czech Republic, and the lowest was in Moldova. Only in the Netherlands, France, Denmark, and Germany were these services (19.0%) present in all regions, with multiprofessional teams providing home care. 24/7 telephone consultations were offered in about 50% of countries, and 24/7 extension services in about 30% of countries by all teams. The results show that many countries had documents on pediatric palliative care but lacked available national plans or strategies.

A review[18] aimed at updating PPC in Latin America across nine databases highlighted several key findings. At the National Children's Hospital in Costa Rica, ethical issues raised many doubts and uncertainties, along with the lack of treatment protocols in PPCs leading to insecurities. In Chile, the scarcity of specialists in the field further complicates the adequate care of these patients. Most studies in this area are from Brazil, Mexico, and Chile. Professional training in PPC is essential for the proper treatment of pediatric patients. The lack of adequately trained professionals creates uncertainties and difficulties in managing these patients effectively, leading to less effective care. According to the article's authors, interventions are needed to expand care plans, conduct more research on administration and management, improve communication during hospitalization and home care, and address the issues of coping and empathy fatigue among palliative care professionals. Another important issue is the need for multidisciplinary teams in PPC to provide comprehensive and quality care to children and their families.

An observational and cross-sectional study[19] explored the barriers to providing PPC in Mexico over four months in 2019. A questionnaire was used to gather information on sociodemographic context, professional experience, and barriers to PPC access. The study included pediatricians, 77% of whom had additional specialization in neuropediatrics, oncology, hematology, or nephrology. The majority of barriers were due to a lack of specialized teams and hospital and home support networks, lack of legal, labor, and financial support, low commitment from authorities and physicians, lack of budget and few PPC teams, lack of knowledge and training in PPC, gaps between legislation and treatment implementation, fragmented care between institutions, workload overload, general prejudices, difficulties with referrals and counter-referrals, telephone support issues, opioid prescription regulation, and 24-hour care, among others.

A scoping review[20] from 2000 to 2023 evaluated the quality of care for PPC patients in Spain in three areas: care structure and process, psychological aspects, and EoL care. Aspects such as communication with patients and families, creation of intimate spaces, emotional support, contact with health teams, and transparent communication can improve PPC quality. From 2000-2009 there were seven publications, from 2010-2019 there were 15, and from 2020-2023 there were 13. The cohorts include 48.6% on professional opinions, 25.7% on patients, 14.3% on family perceptions and opinions, 8.6% on both family and professional opinions, and 2.9% on patients and families. Most studies were from Madrid (45.7%) and Spain, with 22.9% being multicenter studies.

Most studies point to a lack of professional training, with topics like opioid use and pain management, therapeutic effort limitation (LTE), emotional management, communication, and treatment of families and patients needing significant improvement. Furthermore, the education/training of caregivers and the multidisciplinary team is directly linked to improved care quality. Coordination and unrestricted access to the team at any time are also important. Regarding visits, the lack of privacy and limited time suggest the need for individualized spaces to improve care quality.

Emotional issues are also discussed, highlighting the need to assess professional suffering and grief, relieve stress and exhaustion, prevent burnout, and appropriately handle death. Families require psychological care during bereavement and the care process to manage existing conflicts and support moments of uncertainty and emotional suffering, regarding the burden of care and education about the disease and treatment side effects. Feelings of anxiety, stress, helplessness, frustration, sadness, apathy, and anger need to be supported. Another addressed issue is the need for care team presence at the time of death, post-death care for families, and conducting autopsies and/or organ donations. In this context, families value the preservation of memories, farewell rituals, and the presence of the care team at the funeral. Moreover, allowing the family to stay by the bedside at the time of death is important for care quality and is seen positively by 64% of families and 40% of professionals.

A retrospective study[21] evaluated a PPC team at a children's hospital in China from 2012 to 2018, using data from the hospital's clinical data system. Ninety-two patients (54 boys and 38 girls) were included in this study. The median age at referral was 71 months (ranging from 7 months to 16 years). The most common primary diseases were neuroblastoma (29%), acute lymphoblastic leukemia (22%), and acute myeloid leukemia (16%). Of the 92 children, four were alive as of December 2018. Among the 88 deaths, the median time from referral to death was 17 days (ranging from 1 to 218 days). The reasons for referral included malignancy (5.4%), refractory tumor recurrence (82.6%), and severe complications (12%). The places of death included home (31%), hospice ward (36%), local hospital (22%), oncology ward (5%), and emergency room (3.4%).

The most common symptoms were pain, loss of appetite, fatigue, fever, dyspnea, edema/effusion, and bleeding. Due to refractory symptoms, 12 patients received intermittent and moderate sedation. Only two patients with anxiety/depression were taking psychiatric medications. Others with emotional distress were treated with supportive interventions, including listening, relaxation techniques, expressive therapy, and family education. Children unaware of their diagnosis were more anxious or depressed (41.2%) compared to those who knew (14.3%). All families with religious beliefs chose to have an open conversation with their children about their condition and felt that the child died peacefully.

The main barriers observed were parents and medical staff being reluctant to accept the term "palliative care" because it implies "giving up"; the difficulty in estimating clinical prognosis; and families taking time to understand the prognosis. After the child's death, families often regretted not telling the child the truth. When aware of their illness, most children at the institution faced the situation calmly. Two children experienced emotional distress after learning about their illness and felt abandoned.

In this article[22], we examine how pediatric palliative care (PPC) has been implemented across three different states and evaluate whether these institutions are effective in treating patients in accordance with current legislation. The Gulf States Pediatric Palliative Care Consortium (GSPPCC) was initiated in 2019 and comprises interdisciplinary palliative care teams covering all of Louisiana and Mississippi. From the start, changes were made to the wording regarding the benefit of concurrent pediatric palliative care in the Louisiana Manual. The consortium worked with national organizations and advocates to propose updated language, necessitating the creation of policies to translate this new language into practice.

The Pediatric Advanced Care Team (PACT) at Children's Healthcare of Atlanta was established in 2011 to support PPC in Georgia and neighboring states. The team serves inpatients, community hospices, and the Georgia Hospice and Palliative Care Organization (GHPCO) for out-of-hospital and end-of-life care. Concerned with the quality of service, an annual forum on palliative and pediatric palliative care was adapted in 2013 to train professionals in this sector. PACT remains active through the annual forum, identifying strategies for hospices, assisting families, and maintaining real-time communication with Georgia Medicaid regarding ongoing challenges.

END-OF-LIFE CARE

In 2018[23], the Greater Illinois Pediatric Palliative Care Coalition (GIPPCC) was created, uniting existing institutions to form a unified treatment approach. In 2020, the state-funded program included home pediatric palliative care services in the State budget proposal. A retrospective study reviewed four years of medical records at the Pediatric Palliative Care Unit (PPCU) of the University Hospital of Munich, used as an intermediate care unit to conserve ICU resources for life-limiting conditions (LLC). A total of 487 admissions were recorded for 201 patients at the PPCU between April 2016 and November 2020. Patients ranged from neonates to young adults, with 19% being infants, and 12% over 18 years old. Sixty-six percent of patients were referred by a home PPC team, and 9% to an ICU. Thirty-eight percent of patients were admitted repeatedly, with hospital stays ranging from 1 to 186 days, but most lasted less than three weeks. Seventy-eight percent of patients were discharged home, and 84% of patients served by the home PPC team died at home. Most patients had resuscitation orders, with 40% requesting full cardiopulmonary resuscitation (CPR). The main comorbidities were nervous system diseases (38%) and congenital anomalies (34%). Oncological diseases accounted for only 7% of cases. Most patients had non-oncological conditions, likely due to rare and late referrals and rapid disease progression in this group. Clinical experience suggests that improvements in treatments for these groups delayed PPC referrals, resulting in many in-hospital deaths in ICUs.

The most reported symptoms were neurological (88%), with 78% experiencing seizures, 47% spasticity, and 21% dystonia. Permanent gastrointestinal symptoms, primarily constipation, were reported in 80%; dyspnea (61%), pain (54%), and gastrointestinal symptoms (46%) were also common. Symptoms in the subset with oncological diseases (7%) included acute pain (89%), constipation (53%), dyspnea (39%), irritability (28%), urogenital symptoms (17%), respiratory secretions (14%), seizures (11%), acute aspiration (8%), spasticity (6%), and dystonia (3%). Eighty percent of patients relied on medical devices and parenteral medication, 30% had respiratory support, 5% invasive ventilation, and 11% non-invasive ventilation; 75% had dysphagia, and 85% required feeding tubes. Parenteral medication was used in 50% of cases, with the most common drugs being antacids, laxatives, and anticonvulsants, and inhalation therapy was used in 50% of cases with beta-mimetics, corticosteroids, and/or ipratropium bromide. Due to the numerous symptoms and difficulties faced by patients with LLC, medium-support units proved highly effective in managing symptoms and helping children resume normal routines at home. Moreover, these units provide a conducive environment for initiating discussions on pediatric advance care planning (ACP), which can be continued post-discharge with a more structured approach.

PALLIATIVE SEDATION

This is a retrospective study[24] of clinical records of deceased patients treated by the Pediatric Intermediate and Palliative Care Unit (UAIPPM) over a five-year period (2013 to 2017) to analyze the application of palliative sedation and its sequelae. The study describes 20 patients (12.2%) who received palliative sedation and 144 patients who did not receive palliative sedation; of the latter, 93.1% had apparent good symptom control, with a need for sedation in only 6.9% of cases. According to the European Association for Palliative Care (EAPC) and other societies, sedation in pediatric palliative care is defined according to the following protocol (summarized): midazolam with an initial dose of 0.05 mg/kg (maximum of 2 mg) and maintenance with up to 1/3 of the accumulated dose per hour; lorazepam with an initial dose of 0.05 mg/kg every 2-4 hours; levomepromazine with an initial dose of 0.5-1 mg/kg/day in 4 doses (maximum of 75 mg/day); chlorpromazine with an initial dose of 1-2 mg/kg/day in 4 doses (maximum of 40 mg/day); haloperidol 0.1 mg/kg/h; propofol 1 g/kg/hour; thiopental initial dose of 2-5 mg/kg and maintenance of 1-5 mg/kg/h; pentobarbital with an initial dose of 2-3 mg/kg in 30 min (maximum rate of 0.8 mg/h) and maintenance of 1-2 mg/kg/h; dexmedetomidine initial dose 1 mcg/kg (in 10 minutes) and maintenance of 0.1-1 mcg/kg/h; phenobarbital IV: bolus 1-6 mg/kg (maximum 20 mg/kg) in 20 min and maintenance of 1 mg/kg/h or SC: 2.5-5 mg/kg in 24 hours in two doses (maximum 300 mg/dose).

Patients Who Received Sedation: 20 patients, with a mean age of 11.9 years; 12 patients (60%) had cancer, 7 (35%) had neurological diseases, and 1 had a polymalformative syndrome. The mean follow-up time was 2.7 months. Cancer patients did not receive palliative sedation more frequently than those with other diagnoses. Among sedated patients, 17 had more than one uncontrolled symptom at the time of sedation initiation: pain (64.7%) and dyspnea (58.8%); 4 patients had agitation, accompanied by pain or dyspnea; 1 patient had seizures and dyspnea. Sedation was applied in 52.9% of patients in the hospital and 47.1% at home. Continuous sedation was used in 76.4% of patients and intermittent sedation in 11.8%, with an average duration of 1.5 days. The sedation level was classified as deep in 8 patients and superficial in 2. Midazolam was used in 88.2% of cases, either alone (64.7%) or in combination with haloperidol (17.6%) or propofol (5.9%). Adverse events included falls in 16 patients and bronchorrhea in 1 patient. In conclusion, sedation was applied in 12% of study patients, mainly for severe pain, dyspnea, and agitation, using continuous sedation until the end of life, with midazolam being the most used medication.

CONSEQUENCES OF INVASIVE OR NON-INVASIVE INTERVENTIONS

Another retrospective study[25] included all patients with Complex Medical Conditions (CMC) admitted to the Respiratory Intermediate Care Unit of Bambino Gesù Children's Hospital, Research Institute, over 6 months in 2018. The study aimed to evaluate invasive and non-invasive interventions and the prognosis of these patients. Patients were classified according to the four categories highlighted by the Association for Children with Life-Threatening or Life-Limiting Conditions and the Royal College of Pediatrics and Child Health: category 1 includes potentially fatal conditions where curative and palliative treatment are combined for the benefit of the patient; category 2 includes life-threatening diseases where adequate treatment can prolong life and quality of life; category 3 includes progressive conditions with only palliative treatment; and category 4 includes patients with complex health conditions, complications, and early death.

Analyzed Patients: 130 CMC patients were analyzed, with 98 planned admissions and 32 emergency admissions. Common Symptoms: Respiratory and cardiac diseases were the most common symptoms, with associated respiratory, cardiac, and digestive symptoms. Neurological symptoms were less prevalent but included epilepsy and delayed neuromotor development, while urological symptoms were associated with intermittent catheterization. The most common interventions were PEG, catheterization, and NIPPV. There were also high rates of gastrostomy, tracheostomy, bladder catheterization, and central venous access. Hospitalization Duration: Length of stay ranged from 1 to 270 days, with 1 to 7 admissions per year. Hospitalization duration was statistically different for patients without devices (average of 5.5 per year) compared to those with devices (average of 9.5 per year). Among the patients, 41% were under 1 year old, 46% were between 2 and 17 years old, and 13% were 18 years or older. Cancer patients were not included in the study. An important observation was that younger age at symptom onset was associated with a higher number of required devices. This study highlighted the complexity and diversity of patient conditions and the need for adequate ventilatory support and other interventions to improve the quality of life and prognosis of these patients.

OTHERS INTEGRATIVE INTERVENTIONS

A study[26] evaluated the use of medicinal cannabis in six patients with refractory epilepsy and/or chronic pain and/or refractory spasticity, followed at the Pediatric Palliative Care Center in Italy. The study lasted 1 month before the start of cannabis treatment and 12 months during the treatment, with standard treatment maintained alongside the use of cannabis FM2. The protocol included dose increases if pain was not reduced by at least 20%

or if the number/duration of seizures was not reduced by ≥30%. Mild adverse events were reported, including drowsiness, euphoria, restlessness, and tachycardia. It was not necessary to interrupt the dose in any patient; tolerance to use was adequate, and sedation could be an advantage for patients with moderate/severe neurological alterations. Long-term use was not a problem in patients with life-limiting/threatening disease and neurological impairment. All patients experienced a reduction in seizures during the study, and 4 out of 6 patients had a reduction in seizure frequency. The improvement in pain with cannabis use varied among patients, despite an apparent improvement in treatment-resistant pain.

A study[27] conducted in 2019-2020 analyzed data from 186 patients from the Pediatric Palliative Care and Pain Service of the Veneto Region (Italy) to evaluate the psychologist's intervention in PPC for care throughout treatment, showing the complexity of the child's and family's experience in this care. This variety must be taken into account; the psychologist should enhance holistic support with a dedicated competency curriculum. A total of 781 psychological sessions were held, with caregivers (63.5%), patients (18.4%), couples (8.3%), siblings (4.7%), the entire family unit (2.7%), and extended family (2.3%). The themes were relationship management (26.50%) and emotional manifestations (25.22%). The care locations were the hospice (52.5%), online sessions (27.7%), at home (14.6%), and the hospital (5.12%). Data showed that the primary targets of psychological interviews were caregivers (63.51%), with patients being the least common (18.44%). The main focus of these interviews was the emotional state and relationship management of the patients and their families. Discussing the future and the difficult moment of the patient's death was also crucial, making it essential for the psychologist to share individual thoughts, emotions, memories, and wishes. Additionally, each family member plays a fundamental and individual role in this process, making it important to understand each one's perspective.

A cohort study[28] conducted at a PPC reference center in Veneto explored the experiences of children and young people engaging in physical activity and the perspective of their caregivers, seeking the emotional and social impact of this intervention on PPC treatment. Questionnaires were used via apps to assess patients and families. The study included 177 patients in 2020, of whom 16 practiced at least one sport regularly. Most patients received professional physiotherapy (69%) for about 1 hour per week; 50% used wheelchairs, 76% could not walk, 56% could not move independently, 50% were not independent in personal hygiene, and 63% could not dress themselves. However, 94% had no problems with entertainment, 87% had no issues with social interactions, and 69% managed physical and psychological stress well. Most families were of low/middle income.

Children practicing sports reported fatigue and intolerance to effort (71%) and reduced muscle strength (37%). Absence of pain or suffering was reported (71%) and no changes in emotional function (81%). Swimming was practiced by 44%, followed by wheelchair hockey and horseback riding (19%). Football was practiced by 56%. The sports experience was very satisfactory for 81%, and organizing to go to sports practice was good for 76%. Half of the participants reported improved quality of life; parents established bonds with other parents. Children reported pride (44%), happiness (44%), satisfaction (12%), and equality with other parents (6%), encouragement (63%), socialization (12%), equality (12%), and physical and psychological well-being (24%). Half of the participants wished to engage in sports with non-disabled peers; 25% had never considered this opportunity, and the other 25% did not mind practicing sports with disabled individuals. Six children (38%) found the routine exhausting.

For caregivers, 81% considered it reduced the perception of limitations, and for children, 56% had this perception; 88% of parents and 81% of children reported no increased health risks.

Regarding psychophysical health, 94% of parents and 88% of children reported improvements. Additionally, 62% of parents and 81% of children found it a fun activity. The main barriers perceived by caregivers were environmental: inadequate spaces (50%), architectural barriers (62%), cultural barriers (57%), and lack of support outside the family (50%).

LACK OF RESOURCES AND PPC FAILURES

This study[29] evaluated the PPC problem and the main flaws in its strategy. Among them, the highlights are in relation to patient diversity with its small population size making it difficult to achieve significance of the results; the diverse interdependencies and dynamic interactions between children, family members and illness over time; the interpretation of results and measurement considering the variables; many reports about the limitation of qualified labor and infrastructure with a lack of resources necessary for adequate treatment; in addition to the assumed burden of PPC research on participants. To improve these flaws, the study suggests the following seven priorities: "strengthen the training and development of PPC researchers; develop essential infrastructure resources; early measurement of symptoms and measurements of other exposures and outcomes; improve symptom management and quality of life interventions; improved communication; achieving care objectives and decision-making; understand the family impact and facilitate or improve family adaptation and coping; and analyze and improve systems of care, policy and education."

Conclusion

Despite being a simple review of the literature, this article addresses the main points of pediatric palliative treatment today. It brings from the expectations and reality contained in current treatments in different countries, from the first symptoms of referral, the need for more invasive interventions, understanding the roles of each person within the treatment, preparation for the different stages to be faced, to the key points within psychology and the various professionals that improve patients' quality of life. This is all up until end-of-life treatment (EoL) and also with bereavement many times.

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