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Development levels of pediatric palliative care teams and the extent of palliative care understanding and implementation among pediatric oncologists in China

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ABSTRACT

Importance: Pediatric palliative care (PPC) is an interdisciplinary collaboration that focuses on the prevention and relief of patient suffering. PPC has emerged as a critical field of medical expertise and practice. However, no information is available regarding the progress of PPC in the Chinese mainland.

Objective: This study investigated the geographic distribution, team structure, and services of PPC teams in the Chinese mainland. It also investigated the level of understanding and implementation among pediatric oncologists regarding PPC.

Methods: The PPC subspecialty group of the Pediatrics Society of the Chinese Medical Association included 45 PPC teams. The team structure and services were investigated using questionnaires mailed to the team leader of each PPC team. In addition, we sent questionnaires regarding the level of PPC understanding and implementation of PPC practices to 170 pediatric oncologists in 11 hospitals.

Results: The geographical distribution of PPC teams is uneven in China. Most PPC teams are concentrated in the eastern provincial capital of China. Most PPC teams had limited staff and services. The level of PPC understanding was considerably limited across all demographics; most pediatric oncologists reported "some understanding" (n =71, 41.8%) or "poor understanding" (n = 50, 29.4%). Only 62.9% of pediatric oncologists had experience providing advice to family members regarding PPC matters.

Interpretation: China is currently experiencing a critical shortage of PPC resources. Most pediatric oncologists had a limited understanding of PPC and reported limited practical implementation of PPC, which leads to underutilization of PPC resources.

KEYWORDS
Pediatrics, Palliative care, China, Oncologist

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INTRODUCTION

Pediatric palliative care (PPC) is an interdisciplinary collaboration that focuses on the prevention and relief of patient suffering, as well as holistic management of the physical, psychosocial, and spiritual needs of both children and families.[1,2] Over the past two decades, PPC has emerged as a critical field of medical expertise and practice in western nations.[3] Although PPC has experienced exponential growth in the past decade, overall development of this field is limited and demonstrates a lack of balance among countries.[4] In 2011, Knapp et al[5] found that approximately two-thirds of countries worldwide had no known PPC activities, and only 5.7% had a provision that was reaching mainstream providers. According to the International Observatory on End of Life Care, the PPC status in China is Level 2 (i.e., capacity building activities).[5] According to mortality surveillance data-related estimates, 90 600 children in China could potentially benefit from end-of-life PPC in 2017.[6] However, no information is available in China regarding PPC progress and the gaps that still exist in provision. Therefore, this study investigated the geographic distribution, team structure, and services of PPC teams in the Chinese mainland.

Currently, PPC services are mainly provided to patients with cancer. The WHO recommends integration of PPC into standard pediatric oncology care.[7] The level of understanding among pediatric oncologists regarding PPC influences their application of PPC in clinical practice; this application influences PPC service utilization and quality of life among affected patients. Therefore, this study also investigated the level of PPC understanding among pediatric oncologists in China and the degree to which they implement this knowledge in clinical practice.

METHODS

Ethical approval

This study was approved by the Ethics Committee of Beijing Children's Hospital (2018-165). All participants voluntarily completed this anonymous survey and were thus exempt from requirements for written informed consent.

Geographic distribution, team structure, and services of PPC teams

The PPC subspecialty group of the Pediatrics Society of the Chinese Medical Association was established in 2017. It has included 45 member units until June 2019 and is the only PPC-related professional organization in the Chinese mainland. The establishment of this organization constituted the beginning of PPC development in the Chinese mainland. We investigated the geographic distribution, team structure, and services of these 45 PPC teams. Geographic distribution information was obtained from the leader of the PPC subspecialty group. Team structure and services data were collected using questionnaires (Supplementary file S1). Questionnaires were mailed to the team leader of each PPC team. Each organization received only one survey questionnaire.

The questionnaire collected information regarding team establishment time, staff composition, and scope of services offered by the PPC teams. The questionnaire was developed by researchers (Siyu Cai, Xuan Zhou and Xiaoxia Peng) on the basis of literature reviews.[8,9] Pilot tests involving three teams were performed to identify items that were ambiguous or poorly worded.

This survey was conducted from August 2019 to October 2019; the response rate was 100%. Adult hospice units in some general hospitals may accept adolescent patients. Because these teams cannot provide services applicable to children, they were excluded from this study.

Level of PPC understanding and implementation of PPC practices among pediatric oncologists

This study surveyed pediatric oncologists affiliated with hospitals in which the 45 PPC teams were located. Only pediatric oncologists in hospitals with mature PPC teams were eligible to participate because they had the greatest likelihood of possessing knowledge regarding PPC. Therefore, we excluded 12 hospitals with immature PPC teams (i.e., teams comprising doctors alone or teams with only one year of working experience). We sent emails to the remaining 33 hospitals, 11 of which agreed to participate in this study.

The questionnaire survey platform "Wenjuanxing" (www.wjx.cn) was used for data collection. A research summary and questionnaire website link was sent to pediatric oncologists by the director of the pediatric oncology department of each hospital via WeChat. The questionnaire could not be submitted to the platform if a participant only provided some answers or did not complete the required items. The duration of the questionnaire was approximately 5–10 min. Oncologists who responded to this survey were not the members of PPC teams.

The survey items concerned basic information, PPC understanding level, PPC practices, and barriers toward PPC (Supplementary file S2). Before general release of the survey, the questionnaire was reviewed, piloted, revised, and repiloted by an expert panel of pediatric oncologists. This survey was conducted from April 2019 to June 2019. Duplicate questionnaires were deleted based on review of IP addresses. The number of total surveys distributed was not recorded because of the method by which questionnaires were distributed. Thus, the questionnaire response rate could not be accurately calculated.

Statistical analyses

Data were analyzed using SAS version 9.4. Descriptive statistics were used to summarize the data. Frequencies and counts were reported for categorical variables. Means and standard deviations were reported for normally distributed numerical variables. Medians and interquartile ranges were reported for non-normally distributed numerical variables. Normality was determined by Shapiro–Wilk test. Bivariate and multivariate logistic regression analyses were performed to assess the associations between demographic characteristics and level of PPC understanding.

RESULTS

Geographic distribution, team structure, and services of PPC teams

The PPC subspecialty group of the Pediatrics Society of the Chinese Medical Association included 45 PPC teams. These teams covered 22 provinces or municipalities in the Chinese mainland, and their geographical distributions were uneven (Table S1). PPC teams were concentrated in economically developed regions in the eastern part of China. Reports of PPC activities in western China were limited. Forty-four teams belonged to tertiary hospitals and one team belonged to a secondary hospital. The first PPC team was established in 2009 in Shanghai, and most teams (23/45, 51.1%) were established in 2017.

The 45 PPC teams included 300 staff members. Staffing situations reported by PPC teams indicated wide variations regarding the types of professionals and the numbers of people providing PPC services. The mean number of team members was 6.7 (range, 1–14). PPC team members included physicians (100.0% of teams), nurses (88.9% of teams), social workers (37.8% of teams), nutritionists (31.1% of teams), pharmacists (28.9% of teams), psychologists (28.9% of teams), and anesthesiologists (11.1% of teams). Importantly, no teams included spiritual support workers, bereavement specialists, child life specialists, or case managers. Furthermore, approximately one-third of the teams comprised physicians and nurses alone (n = 13, 28.9%), and some teams comprised physicians alone (n = 4, 8.9%). Twenty teams (44.4%) included long-term volunteers (individuals who had received training and performed services more than 3 months), with a median of three volunteers per team.

As shown in Table 1, the services provided by existing PPC teams are limited. These services include pain and symptom management (100.0% of teams), psychological and spiritual support for patients (80.0% of teams), psychological and spiritual support for families (73.3% of teams), bereavement support (33.3% of teams), and advance care planning (31.1% of teams). Consultation care in a home setting was the main pattern of service.

TABLE 1 Services provided by PPC teams

Service	*n* (%)
Service contents	
Symptom management	45 (100.0)
Psychological and spiritual support for patients	36 (80.0)
Psychological and spiritual support for family	33 (73.3)
Bereavement support	15 (33.3)
Advance care planning	14 (31.1)
Service patterns	
Consultation care in home setting	34 (75.6)
Hospice affiliated or not affiliated through the hospital	20 (44.4)
Inpatient consultation	16 (35.6)
Outpatient consultation	12 (26.7)
Dedicated PPC beds	5 (11.1)
Diseases categories	
Curative treatment is possible but may fail (eg, cancer)	45 (100.0)
Progressive conditions without curative treatment (eg, trisomy 13)	8 (17.8)
Chronic conditions with intensive medical long-term therapy (eg, cystic fibrosis)	8 (17.8)
Severe nonprogressive conditions with health complications (eg, severe cerebral palsy)	4 (8.9)

PPC, Pediatric palliative care.

TABLE 2 Demographic characteristics of participating pediatric oncologists

Characteristics	*n* (%)
Sex	
Male	56 (32.9)
Female	114 (67.1)
Specialty	
Pediatric oncologists (Chemotherapy)	130 (76.5)
Surgical oncologists	40 (23.5)
Title	
Professor	25 (14.7)
Assistant professor	36 (21.2)
Attending	45 (26.5)
Resident	64 (37.7)
Academic degree	
Doctor	26 (15.3)
Master	113 (66.5)
Bachelor	31 (18.2)

Palliative care beds or suites were rarely available. Only 11.1% of teams reported access to a dedicated inpatient unit; the median number of beds was 1 (interquartile range, 1–1.5). Few teams (n = 15, 33.3%) had experience in providing PPC to patients with non-cancer diseases. Thirty PPC teams (66.7%) cared for cancer patients only.

Level of PPC understanding and implementation of PPC practices among pediatric oncologists

In total, 170 pediatric oncologists from 11 hospitals completed the questionnaire; their demographic characteristics are shown in Table 2. The median participant age was 35 years (interquartile range, 30–43 years). The level of PPC understanding was considerably limited across all demographics; most pediatric oncologists

TABLE 3 Multivariate logistic regression analysis of level of pediatric palliative care understanding

Characteristics	Estimate	Standard Error	*Wald*	*P*	*OR* (95% *CI*)
Title					
Resident			Ref		
Attending	0.3276	0.5126	0.4085	0.5227	1.388 (0.508–3.790)
Assistant professor	1.2095	0.5263	5.2809	0.0216	3.352 (1.195–9.404)
Professor	1.8298	0.5518	10.9976	0.0009	6.232 (2.113–18.378)
Specialty					
Surgical oncologists			Ref		
Chemotherapy	1.4057	0.5500	6.5315	0.0106	4.078 (1.388–11.986)

TABLE 4 Perceived barriers to PPC

Perceived barrier	*n* (%)
Lack of procedures and referral criteria of PPC	94 (87.9)
Lack of a professional PPC team	87 (81.3)
Lack of financial support	85 (79.4)
Doctors lack knowledge of palliative care	84 (78.5)
Patients and their families lack knowledge of palliative care	84 (78.5)
Lack of support from public policies	83 (77.6)
Lack of insurance coverage	78 (72.9)
Difficulties in obtaining opioid analgesics	57 (53.3)

PPC, Pediatric palliative care.

reported "some understanding" (n = 71, 41.8%) or "poor understanding" (n = 50, 29.4%). Only 35 (20.6%) reported "fair understanding" and 7 (4.1%) reported "good understanding" of PPC. Seven (4.1%) reported "no understanding".

We performed logistic regression analyses to assess the associations between demographic characteristics (i.e., age, sex, specialty, title, and academic degree) and level of understanding. For the purpose of analysis, level of understanding was dichotomized as good understanding (fair or good) or poor understanding (no, poor, or some). Multivariate analysis revealed that specialty (chemotherapy) and high title (professor and assistant professor) were associated with good understanding level (Table 3).

Only 39 participants (22.9%) had received courses or training related to palliative care. Most participants (n = 146, 85.9%) indicated that they desired additional information concerning PPC. Their preferences regarding knowledge acquisition methods included case discussions (84.9%), training projects (80.1%), online courses (71.2%), popular science articles (67.8%), and professional literature/books (58.2%).

In total, 107 oncologists (62.9%) had experience in providing family members advice regarding PPC matters. Of these 107 oncologists, 94 (87.9%) advised parents to seek help from the PPC team, 89 (83.2%) offered suggestions based on their own knowledge of PPC, and 78 (72.9%) advised parents to seek help from hospices.

Pediatric oncologists reported that there were many barriers to the implementation of PPC in China. A summary of perceived barriers to PPC is provided in Table 4. Approximately 87.9% of participants identified a lack of referral criteria and procedure regarding PPC as the most important barrier to providing PPC services. The lack of a professional PPC team was the second most important barrier. Difficulties in the acquisition of opioid analgesics were identified as a barrier by more than half of the participants.

DISCUSSION

Palliative care has not yet been recognized as an important specialty in China; PPC thus remains in its early stages in China. Notably, PPC services are not readily or widely available in Chinese pediatric clinics, and most PPC teams in China have limited staff and services. The PPC concept is not yet established among pediatric oncologists, which has led to insufficient use of PPC.

According to mortality surveillance data-related estimates, 90 600 children in China could potentially benefit from end-of-life PPC in 2017.[6] Furthermore, the PPC needs are two-fold greater in rural areas than in urban areas.[6] However, the PPC subspecialty group only includes 45 member units. Additionally, PPC teams are concentrated in the eastern provincial capital of China. China is currently experiencing a critical shortage of PPC resources, especially in poverty areas. PPC guidelines and recommendations suggest that all large health care organizations serving children with life-threatening conditions should have dedicated interdisciplinary PPC teams, and PPC should be accessible to all children regardless of their location.[10,11] The number of facilities is insufficient to meet the growing demand for PPC services in China. Our findings provide strong evidence that PPC development in China is urgently needed to improve service accessibility. Formal PPC services should be incorporated in the mainstream healthcare system. Policy-level support is essential for establishing PPC services and making those services available to all individuals and communities in China. Remaining gaps include the preparation of PPC standards (e.g., structure, human resources, and environment), promotion of

specialty certification programs for PPC team members, and identification of partnerships between specialist palliative care services and primary/community services. Furthermore, palliative care specialist education programs for doctors and nurses are needed to facilitate the establishment of mature PPC teams. The PPC team of Beijing Children's Hospital has begun to provide training for hospitals in need. The course content includes basic PPC knowledge, as well as critical considerations for establishing a successful PPC program. It is unclear whether the training program can be generalized to other places in China, particularly poor areas with limited healthcare support.

PPC teams in China had considerable gaps in staff composition regarding the types of professionals and the numbers of people providing PPC services. The American Academy of Pediatrics recommends that mature PPC teams should include physicians, nurses, social workers, case managers, spiritual care providers, bereavement specialists, and child life specialists.[12,13] However, approximately one-third of Chinese PPC teams comprised physicians and nurses alone; a few comprised physicians alone. No teams included spiritual support workers, bereavement specialists, child life specialists, or case managers; China has a serious shortage of qualified personnel in these fields. Incomplete team structure leads to limited service content and low service quality. Thus far, only a few teams can comprehensively address the physical, psychosocial, or spiritual needs of children and families. Because relevant professionals are absent, psychological, spiritual, and bereavement support activities are conducted by physicians, nurses or volunteers. Furthermore, with the ease of one-child policy in China, siblings of children with life-threatening conditions require greater attention. Defining the PPC team structure and service contents is an important task for China, which can help teams to improve their service quality.

Considering that most pediatric care occurs outside the hospital, diverse programs and round-the-clock care should be developed.[7,14] The PPC workforce shortage problem is worsened because palliative care needs frequently occur outside of traditional working hours; hence, the palliative care workforce may benefit from flexible work hours and different forms of service (e.g., "online wards").[15-17] During the COVID-19 pandemic, some PPC teams have admitted and remotely managed patients using "online wards" to maintain a safe working environment and ensure service quality.[18]

This survey showed that most pediatric oncologists have limited PPC understanding and conduct limited implementation of PPC, although they work in hospitals with PPC teams. These findings are presumably related to a lack of palliative care education for healthcare providers.[19] Few medical schools in China provide formal training regarding palliative care.[19] National standards are needed with respect to clinical training in palliative care. Among the pediatric oncologists who desired additional information regarding PPC, the most strongly preferred learning method was case discussion. Previous studies have shown that a compelling story could be a strong source of motivation for change. Sharing stories and experiences can help pediatric oncologists to better understand palliative care and implement important aspects in clinical practice.[20]

It is crucial for healthcare providers, hospitals, governments, and policy makers to understand the barriers to PPC. At the national level, there is a need to develop policies, legislation, national standards, clinical guidelines, and referral criteria regarding PPC. At the hospital level, PPC programs should effectively integrate their services into hospital practice. At the PPC team level, multidisciplinary teams should be built to ensure that the physical, emotional, spiritual, and social needs of both children and their families are identified and addressed. From a research perspective, localized PPC service models should be constructed in accordance with Chinese national conditions and needs.

This study had two limitations. First, because of the general lack of data management among 45 PPC teams, the number and characteristics of Chinese patients receiving PPC are unknown. Second, the non-response bias limited the representativeness of the findings.

In conclusion, most PPC teams across the Chinese mainland had limited staff and services, which indicates that China is experiencing a critical shortage of PPC resources. Furthermore, most pediatric oncologists had a limited understanding of PPC and reported limited implementation of PPC, which leads to underutilization of PPC resources.

CONFLICT OF INTEREST

No financial or non-financial benefits have been received or will be received from any party related directly or indirectly to the subject of this article.

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SUPPORTING INFORMATION

Additional Supporting Information may be found online in the supporting information tab for this article.

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