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Abstract

Background: Paediatric palliative care (PPC) focuses on improving the quality of life of children dealing with life-threatening conditions, as well as their families.

Aims: To evaluate the knowledge and attitudes of paediatricians regarding palliative care in Turkey and the impact of PPC units on their confidence and symptom management abilities.

Methods: This was a multicentre descriptive study conducted in 2019. A questionnaire consisting of 24 questions and 4 parts on palliative care was prepared. Paediatricians in hospitals with or without PPC units completed the questionnaire. Analyses were performed using NCSS 10 (2015) software.

Results: There were 199 participants in the study, out of which 55 (27.6%) received palliative care training. One hundred and sixty-seven (83.9%) paediatricians defined palliative care as improving the quality of life of patients in the terminal period, and 77 (38.7%) stated that palliative care can be started after diagnosis. The groups of patients who would benefit from

palliative care were most frequently identified as those with diseases that could not be cured (e.g. cystic fibrosis). Paediatricians with a PPC unit in their work environment, compared with those without a PPC unit, were significantly more competent in pain management (36.8% vs 6.4%, P

Conclusion: PPC units in hospitals contributed to paediatricians' ability to manage symptoms and communicate with families. The number of PPC units should be increased, especially in developing countries such as Turkey.

Keywords: paediatricians, paediatric palliative care, knowledge, pain, symptom management

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Introduction

Paediatric palliative care (PPC) consists of medical and supportive therapies aimed at alleviating the pain suffered by children with life-threatening diseases, as well as their families (1). Improvements have been observed in the quality of life of patients who receive palliative care services (2,3). The frequency of emergency department admissions and invasive/futile treatments were reduced in patients who received PPC compared to those who did not receive PPC (4). Children who receive PPC communicate better with their parents (5). In the past 20 years, there have been significant improvements in paediatric care worldwide.

The American Academy of Pediatrics recommends that all large health institutions that provide services to children with life-threatening conditions should have PPC programmes, and that PPC interventions should be initiated at diagnosis and continued throughout every stage of disease (6). The World Health Assembly has resolved that providing access to PPC is "an

ethical responsibility of health systems" (7).

WHO estimates that more than 56.8 million individuals worldwide need palliative care every year, 7% of whom are children. The majority of children who need palliative care (> 97%) live in low- or low-to-middle-income countries. On a per capita basis, the need for PPC is greatest in the African Region, followed by the Eastern Mediterranean Region (EMR) (8). The palliative care needs of children vary according to the developmental levels of countries (9). In Turkey, there are no national data on the rate of life-restricting diseases, which determines the need for palliative care, and there have been few studies on it. Hospitalization of children with complex chronic conditions in the general paediatric services of tertiary hospitals in Turkey is 9% (10). A high rate of newborn morbidity resulting from a high incidence of consanguineous marriages in Turkey is indication of an increasing need for palliative care (11). Cancer-related child mortality in Turkey ranks fourth after infectious diseases, cardiovascular diseases, and accidents. Cancer is the leading cause of childhood mortality in Turkey, and 30% of children diagnosed with cancer die (12,13). As the number of PPC centres is limited, children who need palliative care are treated in paediatric intensive care units (14).

Palliative care centres in Turkey started to provide services in 2012–2013, and their number increased quickly (15). In the last 20 years, significant improvements have been made to protect children's health in Turkey, as one-third of the population is made up of children (16). However, these efforts are mostly aimed at reducing childhood mortality, and efforts related to PPC are still in their infancy. PPC units should be run by trained and multidisciplinary palliative care teams. This study aimed to determine the knowledge and attitudes of paediatricians, who are members of the PPC team, regarding PPC, and the impact of the presence of PPC units on their confidence and symptom management abilities.

Methods

Study design

This descriptive study was conducted at 5 research and training/medical faculty hospitals that provide training for physicians in different regions of Turkey. Two of these hospitals had a PPC unit. Two groups were defined as hospitals with and without PPC. The study sample comprised child health and diseases faculty lecturers, paediatricians, and residents working in these hospitals. In Turkey, a medical student becomes a paediatrician after completing a 4-year paediatrics residency, and then becomes a subspecialty specialist following 3 years of training. The number of paediatric specialists and residents working in the centres was obtained from the Turkish Ministry of Health. After explaining the study to the participants, 228 questionnaires were administered to the child health and diseases faculty lecturers, attending physicians, and residents, and 208 were completed. Nine questions were excluded from the study because of missing data. The response rate was 82.8% (n = 199).

Questionnaire development

On the first page of the data collection questionnaire, explanatory information about the research and informed consent of the participants was provided. The questionnaire was prepared with the help of existing literature (17,18) and expert opinion. It consisted of 24 questions and 4 parts. Six questions in the first part covered the sociodemographic characteristics of the participants, and 8 questions in the second part included questions about whether the participants received palliative care training, the definition of palliative care, and the availability of palliative care in the hospital where they worked. The attitudes and practices of paediatricians toward palliative care were evaluated in 10 questions in the third part. The questions in the last section were created to collect information on the knowledge levels of paediatricians about palliative care. Participants were asked about their self-perceived confidence in 4 clinical areas: pain, opioid use and its adverse effects, and psychosocial problems of end-stage paediatric patients and their families. The questionnaires were prepared as multiple choice questions.

Before the questionnaire was given to the participants, 25 paediatric specialists and residents developed and pretested the questions and made changes to improve understanding.

Ethics approval

Ethical approval was obtained from the Non-Invasive Clinical Research Ethics Committee of Health Sciences at the University Gülhane Medical Faculty (No; 19/63; Date 2019/04)

Statistical analysis

Data analysis included computation of the mean, standard deviation, median, minimum and maximum values, frequencies, and percentages . Variables between the 2 groups were analysed using the Mann–Whitney U test. Nominal variables were evaluated using the $\chi 2$ test with Yates correction and Fisher's exact probability tests. The significance level was P

Results

A total of 199 participants were included in the study (199/228 = 87.0%). Of the participants, 110 (55.3%) were female and 89 (44.7%) were male (Table 1). The mean age of the participants was 36.3 (9.1) years (range: 23–64 years). According to the job descriptions, 73 (36.7%) of the participants were paediatric residents, 75 (37.7%) were paediatricians and fellowship recipients, and 24 (12.1%) were faculty lecturers. There were 146 (73.4%) participants working in training and research hospitals, and 53 (26.6%) in medical faculty hospitals.

Thirty-eight (19.1%) of the paediatricians stated that they had a PPC system in the hospitals where they worked (Table 2). Fifty-five (27.6%) physicians had received palliative care training; 29 (14.6%) said they received the training in their medical faculties . One hundred and sixty-seven (83.9%) physicians defined palliative care as improving the quality of life of patients in the terminal period, and 77 (38.7%) stated that palliative care can be started after diagnosis. Eighty-eight (44.4%) physicians stated that they preferred pain control as the primary palliative care method, and 156 (78.4%) preferred the use of opioids when pain cannot be controlled with other painkillers.

Participants indicated that patients who benefited from palliative care were most frequently those with diseases that could not be cured (cystic fibrosis, muscular dystrophy, etc.) (94.7% with palliative care service and 88.0% without) (Table 3). A significant difference was found between the 2 groups as to whether they thought that patients with progressive severe neurologic disease (e.g. cerebral palsy) would benefit more from palliative care (89.5% with palliative care service and 70.3% without) (P = 0.027).

Paediatricians working in hospitals with PPC units, compared with those working in hospitals without, reported more confidence in the management of patients' pain and symptoms, and in coping with the psychosocial problems of end-stage paediatric patients and their families (P Tab le 4
). No significant difference was found between the 2 groups regarding opioid use for patients.

All physicians agreed that PPC services should be provided by a multidisciplinary team (Table 5).
One hundred and eighty-eight (95.9%) physicians agreed that the scope of PPC was different from adult palliative care, and 161 (82.1%) agreed with the idea that PPC should be a separate subspecialty.

Discussion

In Turkey, PPC is still in the developmental stage. We interviewed paediatricians to explore their knowledge and attitudes about PPC and assess their confidence in coping with pain, symptom management, and the psychosocial problems of end-stage paediatric patients and their families. Participants working in hospitals that had PPC units reported greater confidence in the management of paediatric patients' pain and symptoms, and in coping with the psychosocial problems of end-stage paediatric patients and their families, compared with those working in hospitals without PPC units. Confidence is related to self-efficacy and pertains to the knowledge

and skill an individual perceives that they possess in a given area. Confidence that is built through experience and success will produce better outcomes for oneself and others (19). There are 2 contributors to self-confidence in paediatricians:: the multidisciplinary team of care providers and the recipients of care.

Mutafoğlu et al. reported that 63% of physicians in a study of 31 paediatric oncology centres in Turkey had insufficient knowledge about palliative care (13). Contro et al. reported that physicians felt inadequate to treat pain and symptoms before a PPC service was provided in a paediatric hospital in the United States of America (20). Similarly, two-thirds of physicians in 11 low- and middle-income Eurasian countries, where PPC services were still in their infancy, did not believe they could meet the physical and emotional needs of palliative care patients or manage their grief (21). Similar to our study, Wu et al. reported that experts and residents felt safe when there was a PPC team in their hospital (22). A study conducted among end-stage paediatric cardiology patients reported that PPC physicians were more competent in communication and symptom management than paediatric cardiologists were (23). In their systematic study, Mitchell et al. demonstrated that PPC services made significant contributions to symptom management in children with life-limiting diseases (24).

Only one-third of physicians who participated in our study stated that they had received training in palliative care. In the directive of the Council of Higher Education in Turkey, the decision about palliative care education for physicians is left to the faculty of medicine. Education about palliative philosophy and principles is not provided in all faculties of medicine, and any such training is related to adult palliative care (15). There is no subspecialty in palliative care after medical education in Turkey. However, physicians and nurses share their palliative care experiences through basic and advanced courses, national and international workshops, congresses, and symposia (15). Providing palliative care training to paediatric specialists and residents significantly increases their confidence in various areas, such as professional knowledge and skills, ease of communication, ethical and legal concerns, and providing emotional support to children with end-stage conditions and their families (6,25). Therefore, our data suggests the need to provide physicians/paediatricians with palliative care training to improve their communication with patients and increase their confidence.

The palliative care approach is misunderstood in the medical community and in society (26). Some studies conducted in Turkey have shown that a significant portion of healthcare professionals perceive palliative care as end-of-life care for terminal patients (15,27,28). PPC guides propose an integrative model for the implementation of palliative care by distinguishing between palliative care and hospice care in the early 2000s. According to this integrated model, palliative care begins at diagnosis and continues throughout the disease, regardless of the outcome (6). Similar to these studies, the paediatricians in our study defined palliative care as improving the quality of life of terminal-stage patients, and only one-third stated that palliative

care should begin at diagnosis.

Only half of the physicians stated that they could talk to families and children about death and life expectancy for end-stage patients. Various studies have shown that doctors and nurses consider themselves inexperienced and inadequately educated to share end-of-life issues with families (29). Nevertheless, when parents are asked to make decisions that affect their children's quality and length of life, physicians are ethically required to provide timely information and a means for the family to make such decisions (22).

Seventy percent of physicians suggested that there should be a legal regulation regarding do-not-resuscitate (DNR) authorization, which supports the findings of a study of paediatric palliative physicians in the Islamic Republic of Iran, another Muslim majority country (15,30). In Turkey, there is no approved ethical directive or guideline on the subject (31). End-of-life decisions are culturally, religiously and socially sensitive and challenging issues (32). Various studies have shown that Muslim physicians are more likely to object to the concepts of withdrawal of life support or artificial nutrition and fatal sedation than non-Muslim physicians are (33). In a study conducted in Turkey, 93% of adult intensive care specialists emphasized that legal DNR regulations should be implemented (34). These studies indicate that there is an urgent need to implement ethical DNR guidelines.

Progress has gained momentum in adult palliative care practices in Turkey, and important steps have been taken to ensure the integration of palliative care into the health system through increased awareness, access to opioid drugs and training activities, and an increasing the number of palliative care centres (15). However, significant obstacles remain to the provision of appropriate palliative care for sick and dying children, such as the lack of adequately trained healthcare professionals, the lack of resources to finance such care, and limited scientific research.

Our study has some limitations. There were a limited number of PPC centres at the time of the study; none of which had been established for more than a year. The study was conducted in 4 cities in four different regions of Turkey: Ankara, the capital city; the metropolis of Istanbul; Erzurum, a developed province in the east of Turkey; and Mersin, a port city in the south of Turkey. The results of this study cannot be generalized to the whole country, therefore, more studies are needed on PPC across the country.

Conclusion

Our study demonstrates the contribution of PPC to paediatricians' ability to manage symptoms and pain and to communicate with families of paediatric patients in Turkey. The number of PPC units should be increased, especially in developing countries such as Turkey. The study shows that paediatricians in Turkey need training on palliative care.

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Competing interests: None declared.

Impact de la présence d'unités de soins palliatifs pédiatriques dans les hôpitaux sur la confiance, les connaissances et les attitudes des pédiatres : cas de la Turquie

Résumé

Contexte : Les soins palliatifs pédiatriques visent à améliorer la qualité de vie des enfants atteints de maladies potentiellement mortelles et de leurs familles.

Objectifs : Évaluer les connaissances et les attitudes des pédiatres concernant les soins palliatifs en Turquie et l'impact des unités de soins palliatifs pédiatriques sur leur confiance et leurs capacités de prise en charge des symptômes.

Méthodes : Il s'agissait d'une étude descriptive multicentrique menée en 2019. Un questionnaire composé de 24 questions et comportant quatre parties sur les soins palliatifs a été préparé. Des pédiatres dans les hôpitaux dôtés ou non d'unités de soins palliatifs pédiatriques ont répondu au questionnaire. Les analyses ont été réalisées à l'aide du logiciel NCSS 10 (2015).

Résultats : Cent quatre-vingt-dix-neuf personnes ont participé à l'étude dont 55 (27,6 %) avaient reçu une formation en soins palliatifs. Cent soixante-sept pédiatres (83,9 %) ont défini les soins palliatifs comme une amélioration de la qualité de vie des patients pendant la période terminale de la vie, et 77 (38,7 %) déclaraient que les soins palliatifs pouvaient être mis en route après le diagnostic. Les groupes de patients qui bénéficieraient de soins palliatifs étaient le plus souvent identifiés comme étant ceux atteints de maladies incurables (par exemple la mucoviscidose). Les pédiatres disposant d'une unité de soins palliatifs pédiatriques dans leur

établissement, par rapport à ceux qui n'en avaient pas, étaient significativement plus compétents dans la prise en charge de la douleur (36,8 % contre 6,4 %, p

Conclusion : Les unités de soins palliatifs pédiatriques dans les hôpitaux contribuaient à la capacité des pédiatres à gérer les symptômes et à communiquer avec les familles. Il faudrait augmenter le nombre d'unités de soins palliatifs pédiatriques dans les hôpitaux, notamment dans les pays en développement comme la Turquie.

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للأطفال المرضى في مرحلة نهاية الحياة (36.8% مقابل 8.4%، والقيمة الاحتمالية أقل من 0.001).

الاستنتاجات: ساهم وجود وحدات للرعاية الملطّفة للأطفال في المستشفيات في قدرة أطباء
الأطفال على علاج الأعراض والتواصل مع الأسر. وينبغي زيادة عدد وحدات الرعاية
الملطّفة للأطفال في المستشفيات، ولا سيما في البلدان النامية مثل تركيا.

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