Impact of presence of paediatric palliative care units in hospitals on the confidence, knowledge and attitudes of paediatricians: the case of Turkey

Nihal Durmaz, Ayse Vehapoglu, Murat Ersoy, Özgül Yiğit, Tuğba Güler and Sevinç Odabas Günes

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 < 0.001), symptom management (42.1% vs 19.2%, P < 0.001), and coping with the psychosocial problems of end-stage paediatric patients (36.8% vs 8.4%, P < 0.001).

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

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

Abstract

Background: Paediatric palliative care (PPC) has resolved that providing access to PPC is “an ethical responsibility of health systems” (7). The World Health Assembly has resolved that providing access to PPC is “an ethical responsibility of health systems” (7). 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

EMHJ – Vol. 28 No. 8 – 2022

Research article
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 χ²
test with Yates correction and Fisher’s exact probability
tests. The significance level was P < 0.05 and was taken
bidirectionally. Analyses were performed using NCSS
version 10 (Kaysville, UT, USA).

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 < 0.001) (Table 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.

**Table 1: Sociodemographic characteristics of the participants**

| Demographic data          | N   | %    |
|---------------------------|-----|------|
| Average age (range) (yr)  | 36.7 (9.1) (23–64) |
| Gender                    |     |      |
| Female/male               | 110/89 | 55.3/44.7 |
| Working time (yr)         |     |      |
| 1–5                       | 64  | 32.3 |
| 6–10                      | 38  | 19.2 |
| 11–15                     | 34  | 17.2 |
| 16–20                     | 24  | 12.1 |
| 21–25                     | 17  | 8.6  |
| 26–30                     | 16  | 7.1  |
| ≥31                       | 7   | 3.5  |
| Institution of employment|     |      |
| Training and research hospital | 146 | 73.4 |
| Faculty of medicine university hospital | 53  | 26.6 |
| Job description           |     |      |
| Paediatric residency      | 73  | 36.7 |
| Paediatric specialist     | 5   | 2.5  |
| Paediatrician             | 70  | 35.2 |
| Paediatric subspecialist  | 27  | 13.6 |
| Lecturer                  | 24  | 12.1 |

**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
Table 3 Preferences of physicians with and without a paediatric palliative unit in their working environment in terms of patient groups who can benefit from palliative care, symptom priority, and communication with end-stage patients

| Paediatric palliative unit | Present (n = 38) | Not present (n = 157) |
|----------------------------|-----------------|----------------------|
| Pain control               | 9 (23.7)        | 78 (49.7)            |
| Anorexia, appetite, and oral intake problems | 3 (7.9) | 16 (10.2) |
| Nausea and gastrointestinal symptoms (constipation, vomiting, diarrhoea) | 9 (24.3) | 13 (8.3) |
| Respiratory symptoms (shortness of breath, cough) | 24 (63.2) | 58 (36.9) |
| Ulcers and other skin complaints | 1 (2.6) | 2 (1.3) |
| Sedation, sleep            | 1 (2.6)         | 2 (1.3)              |

In your opinion as a physician, which patient groups can benefit from palliative care services? (You can check more than one option)

| Patient groups | Present | Not present |
|----------------|---------|-------------|
| Those with curable diseases (cancer, some heart diseases, etc.) | 24 (63.2) | 92 (58.2) |
| Those with diseases that cannot be cured (cystic fibrosis, muscular dystrophy, etc.) | 36 (94.7) | 139 (88) |
| Those with progressive disease (metabolic diseases, etc.) | 26 (68.4) | 115 (72.8) |
| Those with severe non-progressive neurological diseases (cerebral palsy, etc.) | 34 (89.5) | 111 (70.3) |
| Terminal stage paediatric patients | 32 (84.2) | 126 (79.7) |
| Other | 1 (2.6) | 3 (1.9) |

How do you talk about death and life expectancy with end-stage patients?

| Communication method | Present | Not present |
|----------------------|---------|-------------|
| Because families are sensitive enough on these issues, meeting with them is delayed. | 1 (2.6) | 6 (3.9) |
| I speak with children whose age and cognitive functions are of sufficient maturity and families | 17 (44.7) | 71 (45.8) |
| I speak only with the family | 18 (47.4) | 66 (42.6) |
| Other | 2 (5.3) | 12 (7.7) |

Table 4 Reported presence of palliative care unit and self-perceived confidence

| Paediatric palliative care centre | Present | Not present | No | No idea | P |
|----------------------------------|---------|-------------|----|---------|---|
| In pain management               | 14 (36.8) | 110 (70.1) | 18 (47.4) | 37 (23.6) | < 0.001 |
| In symptom management*           | 16 (42.1) | 103 (66.0) | 18 (47.4) | 23 (14.7) | < 0.001 |
| In the management of opioid (morphine, etc.) use and adverse effects | 12 (32.4) | 104 (67.1) | 19 (51.4) | 26 (16.8) | 0.071 |
| Coping with psychosocial problems of end-stage paediatric patients and their families | 14 (36.8) | 97 (63.0) | 16 (42.1) | 44 (28.6) | < 0.001 |

*Anorexia, appetite and oral intake problems, nausea, bed ulcers, constipation.

Table 5 Evaluation of paediatricians' knowledge and attitudes about palliative care

| I agree | I do not agree |
|---------|----------------|
| N (%)   | N (%)          |
| Palliative care should be provided by a multidisciplinary team. | 199 (100) | 0 |
| Paediatric palliative care provides care and support to children with life-threatening illnesses. | 166 (84.3) | 31 (15.7) |
| Emotional enhancement programmes should include not only patients and their relatives but also working healthcare professionals. | 181 (92.3) | 15 (7.7) |
| Palliative care only includes pain control. | 19 (9.6) | 178 (90.4) |
| Palliative care addresses and treats the symptoms themselves without investigating the causes. | 57 (28.9) | 140 (71.1) |
| It is inevitable for individuals working in the field of palliative care to experience burnout because they constantly encounter losses. | 148 (75.5) | 48 (24.5) |
| Palliative care patients are patients who need support and care from time to time during their illness. | 137 (69.9) | 59 (30.1) |
| Paediatric palliative care should be a separate subspecialty. | 161 (82.1) | 35 (17.9) |
| Patients should have the right to not undergo cardiopulmonary resuscitation (DNR) and legal regulations should be made. | 140 (71.4) | 56 (28.6) |
| The scope of paediatric palliative care differs from adult palliative care. | 188 (95.9) | 8 (4.1) |
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.

Funding: None
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 dôts 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 bénéficiaient 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 < 0,001), la prise en charge des symptômes (42,1 % contre 19,2 %, p < 0,001) et la gestion des problèmes psychosociaux des patients pédiatriques en phase terminale (36,8 % contre 8,4 %, p < 0,001).

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.
References

1. Palliative care. Geneva: World Health Organization; 2016 [website] (http://www.who.int/cancer/palliative/en/, accessed 29 May 2021).

2. Friedrichsdorf SJ, Postier A, Dreyfus J, Osenga K, Sencer S, Wolfe J. Improved quality of life at end of life-related to home-based palliative care in children with cancer. J Palliat Med. 2015 Feb;18(2):143–50. https://doi.org/10.1089/jpm.2014.0285 PMID:25401507

3. O’Quinn LP, Giambra BK. Evidence of improved quality of life with pediatric palliative care. Pediatr Nurs. 2014 Nov-Dec;40(6):284–8, 296. PMID:25929123

4. Marcus KL, Santos G, Ciapponi A, Comandé D, Bilodeau M, Wolfe J, et al. Impact of specialized pediatric palliative care: a systematic review. J Pain Symptom Manage. 2020 Feb; 59(2):339–64.e10. https://doi.org/10.1016/j.jpainsymman.2019.08.005 PMID:31404638

5. Mitchell S, Morris A, Bennett K, Sajid L, Dale J. Specialist paediatric palliative care services: what are the benefits? Arch Dis Child. 2017 Oct;102(10):923–9. https://doi.org/10.1136/archdischild-2016-312026. PMID:28377450

6. Section on Hospice and Palliative Medicine and Committee on Hospital Care. Pediatric palliative care and hospice care commitments, guidelines, and recommendations. Pediatrics. 2013 Nov;132(5):966–72. https://doi.org/10.1542/peds.2013-2731. PMID:2448256

7. Integrating palliative care and symptom relief into primary health care: a WHO guide for planners, implementers and managers. Geneva: World Health Organization; 2018 (https://apps.who.int/iris/handle/10665/275459, accessed 16 August 2022).

8. Connor SR, Connor S, Morris C, Jaramillo E. Global atlas of palliative care. 2nd edition. London: Worldwide Hospice Palliative Care Alliance; 2020 (www.thewhpca.org, accessed 16 August 2022).

9. Connor SR, Downing J, Marston J. Estimating the global need for palliative care for children: a cross-sectional analysis. J Pain Symptom Manage. 2017 Feb;53(2):171–7. https://doi.org/10.1016/j.jpainsymman.2016.08.020 PMID:27765706

10. Oztek Celebi FZ, Senel S. Patients with chronic conditions and their complex care needs in a tertiary care hospital. Arch Pediatr. 2021 Aug;28(6):470–4. https://doi.org/10.1016/j.archped.2021.05.001 PMID:34140218

11. Koç İ, Eryurt MA. The causal relationship between consanguineous marriages and infant mortality in Turkey. J Biosoc Sci. 2017 Jul;49(4):536–55. https://doi.org/10.1017/S002132401600033X PMID:28067193

12. Kutluk MT, Yeşilipek MA. Pediatric cancer registry in Turkey (Turkish Pediatric Oncology Group & Turkish Pediatric Hematology Association). J Global Oncol. 2018;4(Suppl. 2). https://doi.org/10.1002/18.25100.

13. Mustafoglu K, Ince D, Kutluk T. The current status of follow-up services for childhood cancer survivors in Turkish pediatric oncology centers. Pediatr Blood Cancer. 2014;61:S291.
14. Bozan G. Dinleyici EÇ, Bozan G. Yarar C, Ulukapı HB, Çarman KB. Palliative care need in pediatric intensive care unit: single center experience. Osmangazi Tıp Dergisi. 2020;42(4):357–62. https://doi.org/10.20515/otd.526609
15. Göksel F, Şenel G, Oğuz G, Özdemir T, Aksakal H, Türkkanı MH, et al. Development of palliative care services in Turkey. Eur J Cancer Care. 2020 Nov;29(6):6–11. https://doi.org/10.1111/ecc.13285 PMID:32715587
16. Turkey Health Transformation Program progress report. Ankara: Republic of Turkey Ministry of Health; 2008 (https://ekut-uphane.saglik.gov.tr/Yayin/182, accessed 16 August 2022).
17. Artino AR Jr, La Rochelle JS, Dezee KJ, Gehlbach H. Developing questionnaires for educational research: AMEE guide No. 87. Med Teach. 2014 Jun;36(6):463–74. https://doi.org/10.3109/0142159X.2014.889814 PMID:24661014
18. Jordan M, Keefer PM, Lee YA, Meade K, Snaman JM, Wolfe J, Kamal A, Rosenberg A. Top ten tips palliative care clinicians should know about caring for children. J Palliat Med. 2018 Dec;21(12):1783–9. https://doi.org/10.1089/jpm.2018.0482 PMID:30289325
19. Bandura A. Health promotion by social cognitive means. Health Educ Behav. 2004 Apr;31(2):143–64. https://doi.org/10.1177/1090198104263660 PMID:15090118.
20. Contro NA, Larson J, Scofield S, Sourke S, Cohen HJ. Hospital staff and family perspectives regarding quality of pediatric palliative care. Pediatrics. 2004 Nov;114(5):1248–52. https://doi.org/10.1542/peds.2003-0857-L PMID:15520103
21. Ehrlich BS, Movsisyan N, Batmunkh T, Kumirova E, Borisevich MV, Krigozov K et al. A multicountry assessment in Eurasia: alignment of physician perspectives on palliative care integration in pediatric oncology with World Health Organization guidelines. Cancer. 2020 Aug 15;126(16):3777–87. https://doi.org/10.1002/cncr.33001 PMID:32530519
22. Wu KL, Friderici J, Goff SL. The impact of a palliative care team on residents’ experiences and comfort levels with pediatric palliative care. J Palliat Med. 2014 Jan;17(1):80–4. https://doi.org/10.1089/jpm.2013.0227 PMID:24410421
23. Balkin EM, Sleeper LA, Kirkpatrick JN, Swetz KM, Coggins MK, Wolfe J, B et al. Physician perspectives on palliative care for children with advanced heart disease: a comparison between pediatric cardiologist and palliative care physicians. J Palliat Med. 2018 Jun;21(6):773–9. https://doi.org/10.1097/jpm.2017.0612 PMID:29412772
24. Mitchell S, Morris A, Bennett K, Sajid L, Dale J. Specialist paediatric palliative care services: what are the benefits? Arch Dis Child. 2017 Oct;102(10):923–9. https://doi.org/10.1136/archdischild-2016-312026 PMID:28374540
25. Peng NH, Lee CH, Lee MC, Huang LC, Chang YC, DeSwarte-Wallace J. Effectiveness of pediatric palliative care education on pediatric clinicians. West J Nurs Res. 2017 Dec;39(12):1624–38. https://doi.org/10.1177/0193945916680615 PMID:27920347
26. Bergrstaesser E. Pediatric palliative care: a reflection on terminology. Palliat Care. 2017 Oct;217(1):1–8. https://doi.org/10.1136/archdischild-2016-312026 PMID:28374540
27. Kafadar D, Ince N, Akcakaya A, Gumus M. Evaluation of managerial needs for palliative care centers: perspectives of medical directors. Asian Pac J Cancer Prev. 2015;16(11):4653–8. https://doi.org/10.7314/apjcp.2015.16.11.4653 PMID:26107219
28. Harputluoğlu N, Özdemir SA, Çelik T. The knowledge of pediatricians about pediatric palliative care. J Pediatr Emerg Intensive Care Med 2020;7. https://doi.org/10.4274/cayd.galenos.2019.95967
29. Harden K, Price D, Duffy E, Galunas L, Rodgers C. Palliative care: improving nursing knowledge, attitudes, and behaviors. Clin J Oncol Nurs. 2017 Oct;11(5):E232–8. https://doi.org/10.1188/17.CJON.E232-E238 PMID:28945719
30. Kadivar M, Mardani-Hamooleh M, Shayestefar S. Evaluation of pediatric residents’ attitudes toward ethical conflict: a cross-sectional study in Tehran, Iran. J Med Ethics Hist Med. 2017 Feb 28;10:2. PMID:28523117
31. Sprung CL, Cohen SL, Sjokvist P, Baras M, Bulow HH, Hovilehto S, et al. End-of-life practices in European intensive care units: the Ethicus Study. JAMA. 2005 Aug 13;290(6):790–7. https://doi.org/10.1001/jama.290.6.790 PMID:12915432
32. Sanchez Varela AM, Johnson LM, Kane JR, Kasow KA, Quintana Y, Coan A et al. Ethical decision making about end-of-life care issues by pediatric oncologists in economically diverse settings. J Pediatr Hematol Oncol. 2015 May;37(4):257–63. https://doi.org/10.1097/MPH.0000000000000271 PMID:25887639
33. İlkılıç İ, Uçar A, Özkaya H. [Palliative medicine with medical, legal, spiritual and ethical dimensions]. Istanbul: Isar Publishing; 2019 (in Turkish).
34. Baykara N, Utku T, Alparslan V, Arslantaş MK, Ersoy N. Factors affecting the attitudes and opinions of ICU physicians regarding end-of-life decisions for their patients and themselves: a survey study from Turkey. PLoS One. 2020 May 20;15(5):e0232743. https://doi.org/10.1371/journal.pone.0232743.