



Nursing Practice and Care Structure for Children and Their Families in Need of Pediatric Palliative and End-of-Life Care in Japan

A Nationwide Survey

Yuko Nagoya, RN, PHN, PhD ○ Mari Matsuoka, RN, PHN, PhD ○
Naoko Takenouchi, RN, PHN, MSN ○ Mika Hirata, RN, PHN, PhD ○
Naoko Arita, RN, PHN, PhD ○ Kazuko Kawakatsu, RN, PHN, PhD ○
Tomoko Furuhashi, RN, PHN, MSN ○ Mitsuyo Ishiura, RN, PHN, MSN ○
Fumi Nakatani, RN, PHN, MSN

Many nurses experience difficulties in pediatric palliative care practice. The study aimed to describe the current situation and structure of pediatric palliative and end-of-life care nursing practices for children and their families in Japan. The research subjects were nurses working in hospitals; facilities for persons with severe physical, motor,

and intellectual disabilities; and home-visit nursing stations. The practice ratio was calculated using a 79-item survey form, and factor analysis was conducted. A total of 113 facilities (acceptance rate: 26.5%) and 777 nurses (response rate: 44.6%) responded. Five items had a "Practicing" ratio of $\geq 90\%$. In factor analysis, 7 domains were identified: "preparing to face the time of death with the child and family," "ensuring child-centered care," "managing symptoms with the child and family," "considering and coordinating for the child's peaceful time of death," "understanding and respecting the culture of the child and family," "assessing the child and family as a whole person," and "performing self-reflection on an ethical issue." Nurses' practice of pediatric palliative care differs by practice domain. It is necessary to reflect on the educational programs under development to improve the quality of life of children and their families.

Yuko Nagoya RN, PHN, PhD, is associate professor, Department of Nursing, Miyagi University, Miyagi, Japan.

Mari Matsuoka, RN, PHN, PhD, is professor, Department of Child Health Nursing, Mie University Graduate School of Medicine, Mie, Japan.

Naoko Takenouchi, RN, PHN, MSN, is PhD student, Department of Human Health Sciences, Kyoto University Graduate School of Medicine, Kyoto, Japan.

Mika Hirata, RN, PHN, PhD, is associate professor, School of Health and Social Services, Department of Nursing, Saitama Prefectural University, Saitama, Japan.

Naoko Arita, RN, PHN, PhD, is associate professor/lecturer, Department of Nursing, Faculty of Nursing, University of Kochi, Kochi, Japan.

Kazuko Kawakatsu, RN, PHN, PhD, is nursing chief, Department of Nursing, Kyoto University Hospital, Kyoto, Japan.

Tomoko Furuhashi, RN, PHN, MSN, is associate professor, School of Nursing, Fukushima Medical University, Fukushima, Japan.

Mitsuyo Ishiura, RN, PHN, MSN, is assistant professor, Faculty of Nursing, Graduate School of Nursing, Kansai Medical University, Osaka, Japan.

Fumi Nakatani, RN, PHN, MSN, is nursing chief, Department of Nursing, Hyogo Prefectural Kobe Children's Hospital, Hyogo, Japan.

Address correspondence to Mari Matsuoka, RN, PHN, PhD, Department of Child Health Nursing, Mie University, 2-174 Edobashi Tsu-city, Mie, 514-8507 Japan (mmatsuoka@med.mie-u.ac.jp).

This work was supported by a grant from JSPS KAKENHI (grant 19H03942).

The authors have no conflicts of interest to disclose.

This is an open-access article distributed under the terms of the Creative Commons Attribution-Non Commercial-No Derivatives License 4.0 (CCBY-NC-ND), where it is permissible to download and share the work provided it is properly cited. The work cannot be changed in any way or used commercially without permission from the journal.

Copyright © 2023 The Authors. Published by Wolters Kluwer Health, Inc. on behalf of The Hospice and Palliative Nurses Association.

DOI: 10.1097/NJH.0000000000000933

KEY WORDS

end-of-life care, nursing, nursing practice, pediatric palliative care, quality of life

The number of children and young people living with life-limiting conditions (conditions that cannot be cured and will cause premature death) and life-threatening conditions is rising.^{1,2} Unlike in adult practice, the proportion of children with childhood cancer in need of palliative care is $<20\%$, with congenital and/or chromosomal disorders and severe cerebral palsy making up a significant proportion.^{3,4} Children with life-limiting conditions require holistic and multidisciplinary services for a long period.⁵ No similar studies have been conducted in Japan; however, the number of children requiring medical care has increased over the past decade to 134 children per million in the population.⁶



Nurses play diverse roles in various settings to provide pediatric palliative care (PPC).^{7,8} It is the same in Japan, where children who need PPC live in various places, such as hospitals, facilities for individuals with severe motor and intellectual disabilities, and their homes. However, there is still a reported shortage of qualified nurses to provide PPC.⁹ Bradley et al¹⁰ found that although neither previous education nor years in practice were associated with more knowledge about palliative care, nurses with specific training in hospice and palliative care services were more likely to practice palliative care with their patients compared with nurses without such training. Pediatric nurses typically do not receive any formal education regarding palliative care or have support systems in place to assist with their feelings surrounding pediatric death.¹¹ The situation is similar in Japan. There are PPC education programs for adult palliative care teams and pediatricians but not for undergraduate nursing students or nurses who engage in pediatric nursing. Furthermore, many nurses experience difficulties with PPC, which may result in children and families in need of PPC not receiving adequate or appropriate care. Therefore, it is necessary to develop an educational program for nurses to improve the nursing practice of PPC in Japan.¹²

The End-of-Life Nursing Education Consortium (ELNEC) project is an international education initiative to improve palliative care that started in the United States.¹³ In addition to the PPC curricula, the project provides various curricula, such as core, oncology, critical care, and geriatrics. Research indicates that the use of the ELNEC curriculum for end-of-life (EoL) and palliative care nursing education is effective for both increasing knowledge and improving attitudes.^{14,15} Currently, the Japanese version of the ELNEC-PPC (ELNEC-JPPC) is being developed by the investigators of this study, who are certified nurse specialists in the Child Health Nursing team with a strong interest and extensive practical experience in PPC. Before the development process began, appropriate procedures were followed to obtain approval from the US ELNEC-PPC faculty for the changes in the Japanese version, and the ELNEC-JPPC was confirmed to ensure consistency with the ELNEC-Japan core program by consulting with faculty members who were involved in its development. In addition, to integrate the characteristics of Japanese nurses' practices in PPC into ELNEC-JPPC, a cross-sectional national-wide survey was conducted. This study aimed to describe the current situation and structure of PPC and EoL care nursing practice for children and their families in need of PPC in Japan.

METHODS

Participants

The survey form was distributed to nurses who were involved in the direct care of children in 16 pediatric hospitals, 99 general hospitals with children's wards, 211 facilities for

persons with severe motor and intellectual disabilities with a hospital bed, and 100 home-visit nursing stations in Japan. These hospitals and facilities care for children who require PPC in an inpatient or outpatient setting. Home-visit nursing stations were selected by convenience sampling, and other facilities covered all applicable facilities.

Data Collection

Between October 2020 and February 2021, introductory letters were sent to explain the objectives of the study to the directors of nursing at the facilities and invite them to participate. With the institutional consent, the directors of nursing distributed the questionnaires to the subjects. Participation in the survey was voluntary.

Ethical Approval

This study was approved by the relevant institutional review board, Ethics Committee (approval number R2538).

Measurements

For the questionnaire, 79 items were extracted from the ELNEC-JPPC. Items were selected by responsible individuals in each module, and face validity was confirmed by 9 researchers who are certified nurse specialists in child health nursing with a strong interest and extensive practical experience in PPC. The responses were given on a 5-point Likert-type scale ("always," "usually," "undecided," "slightly," and "not at all"), with higher scores indicating a greater degree of practice. The answer "no experience" was also accepted. Data on the participant's background, gender, job experience, pediatric nursing experience, cases of dying care, and final moments' care were obtained.

Data Analysis

First, the responses regarding the frequency of practice of PPC were divided into 2 groups: "practicing," which included individuals who responded "always" or "usually," and "not practicing," which included individuals who responded "undecided," "slightly," or "not at all." In the current analysis, the practice rate was calculated after excluding the answer of "no experience."

Second, to clarify the factor structure required for nursing, exploratory factor analysis was performed according to the following procedure. Items with a ceiling effect ($\text{mean} + \text{SD} > 5$) or a floor effect ($\text{mean} - \text{SD} < 1$) were excluded, as were items with a commonality of 0.3 or less. The number of factors was determined using a scree plot. Items with factor loadings of 0.3 or more for 2 or more factors were repeatedly removed.

JMP 15 (SAS Institute Inc, Cary, North Carolina) was used for the statistical analysis.



RESULT

Participant Backgrounds

Nursing directors of the 113 facilities, among 426 facilities, agreed to participate in the study (acceptance rate: 26.5%). Of the 1744 questionnaires delivered to nursing directors, 777 were returned (response rate: 44.6%). Table 1 summarizes participants' background information.

Nursing Practice Ratio in PPC

Five items had a "practicing" ratio of 90% or higher. These 5 items included "assessing the child's physical distress" and "relieving the child's physical distress" for physical distress relief, "ensuring that someone intimate to the child is present during their last moment" and "creating an environment where the child and his/her family can spend their time quietly and comfortably after the death of the child" for the time of death, and "perceiving the child's verbal/nonverbal thoughts." Sixteen items had a "practicing" ratio of less than 50% (Table 2).

The Concept of Nursing for Children and Their Families in Need of PPC

Table 3 shows the results of exploratory factor analysis, factor names, and average practice levels for each subscale.

Nursing practice in PPC consisted of 7 factors and 52 items. Seven factors included "preparing to face the time of death with the child and family," "ensuring child-centered care," "managing symptoms with the child and family," "considering and coordinating for the child's peaceful time of death," "understanding and respecting the culture of the child and family," "assessing the child and family as a whole person," and "performing self-reflection on an ethical issue."

DISCUSSION

Nursing Practices of PPC in Japan

Nurses' practice of PPC differs by practice domains. Five items had a "practicing" ratio of 90% or higher. Of the 5 items, 2 concern care at the death of a child. The care at death for a child and their family is essential to link bereavement care of the parents. This study showed that Japanese nurses highly practice care at the death of a child. Symptom management is an essential element in palliative care.¹⁶ In the current study, there was a high level of practice in capturing verbal and nonverbal child complaints. There is a possibility that nonverbal communication is carried out in daily care in the field of pediatric nursing, such as care for children in the process of language development¹⁷

TABLE 1 Participants' Characteristics (n = 777)

	Mean ± SD or n (%)
Affiliation facility	
Pediatric hospitals	187 (24.1)
General hospitals	360 (46.3)
Facilities for persons with severe motor and intellectual disabilities	201 (25.9)
Home-visit nursing stations	29 (3.7)
Sex	
Male	51 (6.6)
Female	725 (93.4)
Job experience, y	15.04 ± 9.21
Pediatric nursing experience, y	10.19 ± 7.48
Cases of the phase of dying care	
0	82 (10.6)
1-5	362 (47.0)
6-10	138 (17.9)
11-15	62 (8.1)
≥16	127 (16.5)



TABLE 2 The Practice Ratio of Less Than 50% Item

Item	"Practicing," n (%)
Assessing the siblings' grief of the bereavement of his/her brother/sister	302 (48.9)
Discussing explanations for the siblings with the child's family	331 (48.4)
Discussion with the parents to explain to the child's siblings that the child is dying	278 (48.4)
Taking care of the nurse himself/herself to grieve consciously	307 (46.2)
Understanding the social and medical situations surrounding children and his/her family	344 (46.0)
Relieving the child's social distress	329 (44.3)
Educating the child and their family regarding symptom management	305 (44.1)
Perceiving the siblings as targets of care	302 (41.7)
Using an assessment scale that is tailored to the specific child	281 (40.8)
Assessing the child's spiritual distress	286 (40.3)
Assessing the grief of the surrounding people (grandparents, friends, etc) who are affected by the bereavement of the child	247 (39.6)
Managing the nurse's own ethical dilemma	276 (37.7)
Relieving the child's spiritual distress	241 (33.8)
Coordinating supports for parents and siblings who have experienced the bereavement	188 (32.6)
Comprehending the child's understanding and/or perspective about death	187 (30.6)
Talking with family members about the child's death	194 (30.1)

and care for severely retarded children who have difficulty expressing linguistically.^{18,19} This study showed that the level of practice for physical pain was high, but simultaneously, it became clear that the ratio of using an assessment scale tailored to the specific child was low. It may be necessary to strengthen education using ELNEC-JPPC to appropriately assess the symptoms of individual children.

Most of the items with a practicing ratio of 50% or less were related to psychosocial pain relief, sibling support, and nurses' self-management. Providing psychosocial support for the child is as essential as providing relief against physical symptoms. Children's psychosocial care needs differ from adults' needs,^{20,21} and younger children have difficulty in verbal communication. Therefore, it is possible that nurses find it difficult to grasp the psychosocial distress of children. The idea that open communication with the child and their family is the best way to grasp the psychological, social, and spiritual distress of the child and family is becoming more popular. However, in communicating with children who need palliative care, the nature of the context requires careful consideration of what is best for the child, the family, and the health care professionals, considering their beliefs and cultural background.²² In addition,

there is a possibility that in Asian cultures, including Japan, ideas of autonomy for children are different from those of Western countries. Wiener's study indicated that there are deep-rooted values, patterns of parents protecting their children by blur boundaries between mother and child, and a tendency to believe that it is better not to talk about death or a poor prognosis that might frighten children.²³ The difficulty in grasping the psychosocial distress indicated by the results of this study may demonstrate this way of thinking in Japan. The ELNEC-JPPC needs to improve its assessment and care by including content on dealing with psychosocial distress in children that takes Japanese cultural contexts into account. However, further research is required to investigate the impact of cultural differences on PPC.

There is a possibility that the Japanese hospital visitation system and length of hospital stay influenced the low practice rate background of items related to sibling support. In Japan, many facilities restrict sibling visits because of infection control. In addition, hospitalization is longer than that in other countries. Previous studies have shown that sibling support is an important element of PPC.^{24,25} Even under visitation restrictions, it is possible to indirectly address siblings, such as asking parents about the siblings or



TABLE 3 The Concept of Nursing for Children and Their Families in Need of Pediatric Palliative Care: Exploratory Factor Analysis

Domain Item	β	Communality
I. Preparing to face the time of death with child and family (mean \pm SD, 3.44 \pm 1.05; α = .90, CR = 18.18)		
Assessing the siblings' grief of the bereavement of his/her brother/sister	0.88	0.85
Assessing the grief of the surrounding people (grandparents, friends, etc) who are affected by the bereavement of the child	0.82	0.73
Coordinating supports for parents and siblings who have experienced the bereavement	0.68	0.55
Assessing the dying child's own loss and grief	0.63	0.60
Assessing the parents' grief of the bereavement of the child	0.56	0.62
Considering the effects encountered by the family during the bereavement of the child	0.46	0.55
Taking care of the nurse himself/herself to grieve consciously	0.42	0.34
Discussion with the parents to explain to the child's siblings that the child is dying	0.39	0.50
II. Ensuring child-centered care (mean \pm SD, 3.82 \pm 0.83; α = .89, CR = 20.87)		
Recognizing and respecting the child's preferences during daily care	0.81	0.69
Ensuring that the child has opportunities to express his/her thoughts and wishes	0.79	0.72
Protecting the child's right to self-determination	0.75	0.65
Providing easily understandable explanations to facilitate the child's understanding	0.63	0.50
Sharing in the child's wishes and hopes	0.40	0.46
Protecting the rights of the child who is receiving medical care	0.37	0.40
Grasping the meanings and reasons of the child's preference when they choose something	0.37	0.55
Respecting the child's wishes and preferences until the last moment	0.34	0.42
III. Managing symptoms with child and family (mean \pm SD, 3.79 \pm 0.83; α = .89, CR = 20.15)		
Assessing aggravating and alleviating factors for symptom management	0.84	0.68
Assessing barriers to symptom management	0.70	0.62
Combining pharmacological and nonpharmacological interventions to relieve symptoms	0.68	0.43
Continuous and regular assessments for symptom management	0.49	0.46
Managing the child's symptoms with their family's assistance	0.45	0.51
Perceiving the child's verbal/nonverbal thoughts	0.41	0.31
Supporting and facilitating the child's self-care ability for symptom management	0.40	0.44
Educating the child and their family regarding symptom management	0.40	0.43
Focusing on the symptoms that the child finds most distressing	0.39	0.29
Supporting and facilitating the family's self-care ability for the child's symptom management	0.35	0.53
Assessing what the child values	0.35	0.44

(continues)



TABLE 3 The Concept of Nursing for Children and Their Families in Need of Pediatric Palliative Care: Exploratory Factor Analysis, Continued

Domain Item	β	Communality
IV. Considering and coordinating for the child's peaceful time of death (mean \pm SD, 3.95 \pm 0.83; α = .87, CR = 15.72)		
Taking care of specific symptoms that become observable when death is near	0.88	0.82
Assessing specific symptoms that are observable when death is near	0.85	0.80
Discussions about what the family can currently do for their child when death is near	0.56	0.55
Creating a place and time for child and his/her family to spend their last time	0.56	0.46
Sharing information about the child's current medical condition and educating the family about the signs and symptoms of the dying process	0.50	0.44
V. Understanding and respecting the culture of child and family (mean \pm SD, 3.79 \pm 0.83; α = .89, CR = 20.12)		
Assessing the family's values, beliefs, and customs that affect the child's care	0.69	0.64
Providing medical and general care that considers the child's illness experiences, family values, beliefs, and customs	0.62	0.61
Assessing the parenting and social environments which the child has grown up in	0.56	0.55
Assessing the relationship and communication between families	0.56	0.53
Acknowledging the cultural diversity of each child, his/her families, and the health care providers	0.54	0.48
Grasping the meanings and reasons for the family's preference when they choose something	0.39	0.55
Understanding and providing information that the family requires	0.38	0.45
Sharing in the family's wishes and hopes	0.32	0.45
VI. Assessing child and family as the whole person (mean \pm SD, 3.70 \pm 0.84; α = .84, CR = 16.45)		
Perceiving the child as a separate person	0.61	0.56
Supporting the child's independence in life by being themselves, no matter the time or place	0.56	0.45
Perceiving the entire family accurately	0.55	0.52
Understanding the social and medical situations surrounding children and his/her family	0.52	0.49
Considering the child's growth and development	0.47	0.39
Perceiving the siblings as targets of care	0.45	0.38
Providing the child with family-centered care	0.42	0.41
Being able to perceive the interdisciplinary team approach	0.31	0.31

(continues)



TABLE 3 The Concept of Nursing for Children and Their Families in Need of Pediatric Palliative Care: Exploratory Factor Analysis, Continued

Domain Item	β	Communality
VII. Performing self-reflection on an ethical issue (mean \pm SD, 3.48 \pm 0.85; α = .83, CR = 13.12)		
Recognizing the nurse's own ethical dilemma	0.89	0.77
Managing the nurse's own ethical dilemma	0.81	0.70
Recognizing ethical issues	0.63	0.53
Recognizing the nurse's own beliefs and values	0.39	0.41

Standardized regression coefficients were calculated by using exploratory factor analysis (least-squares method, Quartmin rotation). β is standardized regression coefficient, Communality refers to final communality estimates, and α is Cronbach α coefficient. The higher the mean for each domain, the higher the practice rate. Abbreviation: CR, contribution ratio.

teaching parents how to support siblings. To further improve sibling care in the future, an interdisciplinary team approach is needed. The practice rates of the nurses' own grief care and self-management for ethical dilemmas were low. There may be a lack of self-care approaches at both personal and organizational levels in Japan, suggesting the need for education for effective self-care practices.

The Concept of Nursing for Children and Their Families in Need of PPC

The concept of nursing care for children and their families in need of PPC consisted of 7 factors and 52 items. Three of these domains were concepts related to the basic posture of pediatric nursing: "ensuring child-centered care," "understanding and respecting the culture of child and family," and "assessing child and family as the whole person." The other 3 domains were concepts related to PPC and EoL care: "managing symptoms with child and family," "preparing to face the time of death with child and family," and "considering and coordinating for the child's peaceful time of death." The interdisciplinary approach and sibling support are two of the important factors in palliative care.²⁴⁻²⁶ In our results, the interdisciplinary approach was included in "assessing child and family as the whole person" domain, and sibling support was included in "assessing child and family as the whole person" and "preparing to face the time of death with child and family." All 6 domains included the role of nurses in palliative care, as shown in previous studies. As a result of exploratory factor analysis, "performing self-reflection on an ethical issue" was extracted as one of the concepts of nursing practice in PPC. The other domains were aimed at caring for children and their families, but only this domain was about the nurses' own reflection. Especially during the EoL phase, ethical issues are more likely to occur.²⁷ Furthermore, in the pediatric field, conflicts are likely to occur owing to child advocacy

and decision-making issues.²⁸ Therefore, this domain is an important concept in the nursing practice of PPC.

LIMITATION

This study has several limitations. This survey clarified the current state of nursing practice and its structure in Japan. A future task is to consider these related factors (eg, job experience and affiliation facility). This survey was conducted from 2020 to 2021, when COVID-19 was prevalent in Japan and was under an unusual medical system. Factors attributed to the COVID-19 epidemic, such as strengthened visitation restrictions and changes in the work environment, might have influenced the responses of sibling support and nurses' self-management. However, this was the first national survey in Japan, and it was possible to clarify the current status and structure of PPC for improving nursing education in the future. Based on this study, future research could be conducted to evaluate changes in nursing practice before and after taking an educational program and whether sufficient care has been delivered to children and their families in need of PPC.

CONCLUSION

The findings of this study reveal the actual situation and the structure of PPC and EoL care nursing practice for children and their families in need of PPC in Japan. Nurses' practice of PPC differs by practice domain. The concept of nursing care for children and their families who need PPC consisted of the basic attitude of pediatric nursing, PPC, and EoL care. To improve the quality of life of children and their families, it is necessary to investigate the causes of domains that are not practiced daily and to consider incorporating educational content that focuses on them into ELNEC-JPPC. In addition, it is important that the educational content takes Japanese culture into account (eg, communication with children and the visitation system during hospitalization).



Unfurling ELNEC-JPPC in Japan will improve the quality of life for children and families who need PPC.

Acknowledgments

We are grateful to Dr Keiko Tamura and Dr Sayaka Takenouchi for consulting with the US ELNEC-PPC faculty and helping to obtain their approval for the changes in the Japanese version.

References

- Fraser LK, Gibson-Smith D, Jarvis S, Norman P, Parslow R. *Make Every Child Count! Estimating Current and Future Prevalence of Children and Young People With Life-Limiting Conditions in the United Kingdom*. York, United Kingdom: University of York; 2020.
- Mitchell S, Morris A, Bennett K, Sajid L, Dale J. Specialist paediatric palliative care services: what are the benefits? *Arch Dis Child*. 2017;102:923-929. doi:10.1136/archdischild-2016-312026.
- Song IG, Kwon SY, Chang YJ, et al. Paediatric palliative screening scale as a useful tool for clinicians' assessment of palliative care needs of pediatric patients: a retrospective cohort study. *BMC Palliat Care*. 2021;20:73. doi:10.1186/s12904-021-00765-8.
- Hunt A, Coad J, West E, et al. The big study for life-limited children and their families—final research report. Kelly K, Woodhead S (eds). p20, Fig5&6. <https://www.togetherforshortlives.org.uk/app/uploads/2018/01/ProRes-The-Big-Study-Final-Research-Report.pdf>. Accessed June 10, 2022.
- Fraser LK, Gibson-Smith D, Jarvis S, Norman P, Parslow RC. Estimating the current and future prevalence of life-limiting conditions in children in England. *Palliat Med*. 2021;35:1641-1651. doi:10.1177/0269216320975308.
- Tamura M. Iryoutekikeazi ni taisuru zittaityousa to Iryou. Fukushi. Hoken. Kyouiku nado no renkei ni kansuru kenkyu [Fact-finding survey of children requiring medical care and research on collaboration between medical care, welfare, health and education, etc.]. Ministry of Health, Labour and Welfare. <https://mhlw-grants.niph.go.jp/project/27264>. Accessed November 11, 2022.
- Akard TF, Hendricks-Ferguson VL, Gilmer MJ. Pediatric palliative care nursing. *Ann Palliat Med*. 2019;8(suppl 1):S39-S48. doi:10.21037/apm.2018.06.01.
- L Chambers, A Goldman, eds. *A Guide to Children's Palliative Care*. 4th ed. p28, 3–3. The nursing workforce. <https://www.togetherforshortlives.org.uk/app/uploads/2018/03/TfSL-A-Guide-to-Children%E2%80%99s-Palliative-Care-Fourth-Edition-5.pdf>. Accessed June 10, 2022.
- Together for Short Lives. *The State of Children's Palliative Care Nursing in 2017*. Bristol, United Kingdom: Together for Short Lives; 2018. https://www.togetherforshortlives.org.uk/wp-content/uploads/2018/03/PolRes_Together_for_Short_Lives_-_The_state_of_children_s_palliative_care_nursing_in_2017.pdf. Accessed June 10, 2022.
- Bradley EH, Cherlin E, McCorkle R, et al. Nurses' use of palliative care practices in the acute care setting. *J Prof Nurs*. 2001;17:14-22.
- Negrete TN, Tariman JD. Pediatric palliative care: a literature review of best practices in oncology nursing education programs. *Clin J Oncol Nurs*. 2019;23:565-568. doi:10.1188/19.CJON.565-568.
- Maeda H. Syouni Zaitakuiyou No Genzyou to Kadai. [Current status and issues of pediatric home medical care]. National Center for Child Health and Development. <https://www.mhlw.go.jp/content/10800000/000491021.pdf>. Accessed January 13, 2022.
- American Association of Colleges of Nursing. About ELNEC. <https://www.aacnnursing.org/ELNEC/About>. Accessed June 10, 2022.
- O'Shea ER, Mager D. End-of-life nursing education: enhancing nurse knowledge and attitudes. *Appl Nurs Res*. 2019;50:151197. doi:10.1016/j.apnr.2019.151197.
- Jacobs HH, Ferrell B, Virani R, Malloy P. Appraisal of the pediatric End-of-Life Nursing Education Consortium training program. *J Pediatr Nurs*. 2009;24:216-221. doi:10.1016/j.pedn.2008.03.001.
- Sholjakova M, Durnev V, Kartalov A, Kuzmanovska B. Pain relief as an integral part of the palliative care. *Open Access Maced J Med Sci*. 2018;6:739-741. doi:10.3889/oamjms.2018.163.
- Feldman HM. How young children learn language and speech. *Pediatr Nurs*. 2019;40:398-411. doi:10.1542/pir.2017-0325.
- McFadd ED, Hustad KC. Communication modes and functions in children with cerebral palsy. *J Speech Lang Hear Res*. 2020;63:1776-1792. doi:10.1044/2020_JSLHR-19-00228.
- Fox MA, Ayyangar R, Parten R, Haapala HJ, Schilling SG, Kalpakjian CZ. Self-report of pain in young people and adults with spastic cerebral palsy: interrater reliability of the revised Face, Legs, Activity, Cry, and Consolability (r-FLACC) scale ratings. *Dev Med Child Neurol*. 2019;61:69-74. doi:10.1111/dmcn.13980.
- Wiener L, Devine KA, Thompson AL. Advances in pediatric psychooncology. *Curr Opin Pediatr*. 2020;32:41-47. doi:10.1097/MOP.0000000000000851.
- Mori M, Sasahara T, Morita T, et al. Achievement of a good death among young adult patients with cancer: analyses of combined data from three nationwide surveys among bereaved family members. *Support Care Cancer*. 2019;27:1519-1527. doi:10.1007/s00520-018-4539-9.
- Stein A, Dalton L, Rapa E, et al. Communication with children and adolescents about the diagnosis of their own life-threatening condition. *Lancet*. 2019;393:1150-1163. doi:10.1016/S0140-6736(18)33201-X.
- Wiener L, McConnell DG, Latella L, Ludi E. Cultural and religious considerations in pediatric palliative care. *Palliat Support Care*. 2013;11:47-67. doi:10.1017/S1478951511001027.
- Widger K, Brennenstuhl S, Duc J, Tourangeau A, Rapoport A. Factor structure of the Quality of Children's Palliative Care Instrument (QCPCI) when complete by parents of children with cancer. *BMC Palliat Care*. 2019;18:23. doi:10.1186/s12904-019-0406-9.
- Chin WL, Jaaniste T, Trethewie S. The role of resilience in the sibling experience of pediatric palliative care: what is the theory and evidence? *Children (Basel)*. 2018;5:97. doi:10.3390/children5070097.
- Hagan TL, Xu J, Lopez RP, et al. Nursing's role in leading palliative care: a call to action. *Nurse Educ Today*. 2018;61:216-219. doi:10.1016/j.nedt.2017.11.037.
- Akdeniz M, Yardımcı B, Kavukcu E. Ethical considerations at the end-of-life care. *SAGE Open Med*. 2021;9:20503121211000918. doi:10.1177/20503121211000918.
- Santoro JD, Bennett M. Ethics of end of life decisions in pediatrics: a narrative review of the roles of caregivers, shared decision-making, and patient centered values. *Behav Sci (Basel)*. 2018;8:42. doi:10.3390/bs8050042.