Basic Research

Effect of Palliative Care Training Program on Pediatric Nurses' Perception among Children with Terminal Illness

Fatma Mohamed Mohamed 1, Tanazor Hemdan Abdelhamed 2

1Ass.professor of pediatric nursing, Faculty of nursing Ain Shams university, Cairo, Egypt 2Lecturer of Pediatric Nursing, Faculty of Nursing, Modern University of Technology & Information (MTI), *Cairo*, *Egypt*.

tanazor.morsi@nur.mti.edu.eg

Abstract

Introduction: Palliative care has grown increasingly significant in nursing management as the number of children requiring support in their final stages of life has increased. A deficient education and a negative attitude among nurses are some of the most prevalent barriers to excellent palliative care. AIM: To measure the effect of palliative care training programs on pediatric nurses' perception among children with a terminal illness. **Methods:** A quasi-experimental research design with study, the study was conducted at dialysis intensive care units and pediatric intensive care units at children hospitals affiliated with Ain Shams University. A study was conducted on 100 nurses who directly provided care to terminally ill children. Researchers used tools that included characteristics, knowledge, and attitude level of nurses. **Results**: In terms of total knowledge, more than two-thirds of nurses (67%) have a low level of knowledge before program intervention. On other hand and over one-third (39%) have a good level of knowledge after program intervention. According to the findings, there was a highly statistically significant change (P 0.01**) in nurses' attitudes after intervention in all aspects measured. **Conclusion:** This study found that pediatric nurses' understanding, and practice of palliative care improved significantly after completing a training program. There was also a strong association between pediatric nurses' knowledge and attitudes toward palliative care. Recommendation: Periodical revision of training program about terminally ill children, and guide nurses for their perception concerning the care of terminally ill children.

Keywords: Attitude; Knowledge; Palliative care; Perception; Pediatric nurses.

Introduction

Palliative care is a patient-centered strategy that aims to improve the quality of life of children and their parents facing a life-threatening problem by preventing and alleviating suffering through early monitoring, accurate reflection, and treatment of pain and other problems such as physical, psychosocial, and spiritual. Global healthcare systems face a significant challenge in providing adequate palliative care. (**Kim et al., 2020**)

Palliative care has been offered as a concept of continuous care that begins with disease diagnosis and continues until the child death. It is becoming more popular across the world because of the pediatric population, an increase in the frequency of chronic illnesses, and a growing interest in quality of life. Pediatric palliative care is characterized as a distinct, closely linked specialty to adult palliative care (**Achora & Labrague**, **2019**). Its goal is to alleviate the pain of pediatric patients who are suffering from chronic and life-threatening illnesses. Nurses, physicians, social workers, chaplains, and other therapists may be needed to work as multi-discipline teams to achieve the goals of palliative care. Pediatric palliative care is broadening its scope of practice to cover not just dying children, but also children with life-threatening illnesses. (**Jeong et al.**, **2020**).

The aims of palliative care, according to nurses working in pediatric intensive care units, include good pain management, lowering patient suffering, supporting a dignified death, and efficient communication between the health care team, the child, and their family. Furthermore, they cite challenges to the palliative care they give, such as a lack of communication among physicians, nurses, and families; a lack of a clear treatment plan; uneasiness with death and dying; and a lack of understanding about end-of-life practices and services. (**Knighting et al., 2019**).

To provide greater palliative care, it is critical to integrate knowledge, skills, and positive attitudes regarding palliative care. Nurses who are informed, skilled, and at comfort providing palliative care may improve the quality of life and satisfaction of children and families in hospital settings. (Cheng et al., 2021). As a result, guidelines must be developed and implemented, as well as a practical training program designed to generate trained nursing practitioners capable of providing palliative care. (Lafond et al., 2022)

Education and training in palliative care not just quality of care provided, but also the extent to which healthcare professionals work together as a team. Palliative care training is a difficult practice for both trainers and trainees because a real-life situation can never be reproduced in an educational setting. (Balicas, 2018).

The study discovered differences in health workers' knowledge and abilities. Professionals who felt poorly to assertively give palliative care indicated a need for extensive and effective

training. Moreover, parents have expressed their dissatisfaction with palliative care and endof-life care. (**Lin et al., 2021**). Nurses have a higher chance of interacting with palliative care patients than other health care professionals. Because there is such a high demand for such specialized services among patients and society, establishing a caring program for nurses involved in the topic is just as important as their technical education, and should therefore be included in a nursing education program. (**Li, Chhabra & Singh, 2021**).

Perceptions of medical practitioners who work as part of interdisciplinary groups to offer patient-centered care are critical to establishing the present status of pediatric palliative care and identifying gaps and potential for improvement. Nurses are expected to provide the most appropriate information to children and their families throughout crucial circumstances; as a result, they must be proficient in caring for children with life-threatening illnesses and aiding patients in making the best decisions. (**Dehghani et al., 2020**).

Nurses should focus on improving child comfort and reducing physical discomfort. They should, however, be aware of how to assist the child and their families in determining whether palliative care is suitable. Effective palliative care training for nurses increases their ability to provide high-quality care while maintaining dignity, acceptance, and sincerity. (Menekli et al., 2021)

Aim of the study

The study aimed to measure the effect of palliative care training programs on pediatric nurses' perception among children with a terminal illness through:

- Assessing nurses' knowledge and practice about palliative care.
- Assessing the nurses' perception regarding palliative care.
- -Develop and implement a palliative care training program for pediatric nurses.

Hypotheses:

The training program had a beneficial effect on pediatric nurses' perception of palliative care.

Materials and MethodMaterials:

Design: A quasi-experimental design was used to conduct his study.

Sample Size: Based on an Open Epi with a 95% confidence interval, type 1 alpha error of 0.05, type 2 (1-B error of 80%), and a 50 percent response distribution,

Setting: The study was conducted at dialysis intensive care units and pediatric intensive care units at children hospitals affiliated to Ain Shams University. the projected sample size was 100 Nurses.

Participants: A convenience sample of 100 pediatric nurses who provide direct care for children in the previously mentioned setting were chosen based on their convenience, regardless of their age, gender, or years of experience.

Tools of data collection:

I- **Knowledge & perception questionnaire**: Following a thorough examination of the literature, the researchers designed an Arabic-interviewed questionnaire. It was made up of four components, which were as:

Part I: Characteristics of the studied nurses as age, gender, marital status, qualifications, experience, position, the existence of palliative care team and affiliated ward

Part II: Knowledge level: it was developed by researchers after literature reviews as **Parajuli & Hupcey, 2021**. This part included 18 closed-ended questions at MCQ form divided into five domains as; Concept of palliative care (4 questions), Principle of palliative care (4 questions), Psychological and spiritual (3 questions), Management of pain and other symptoms (3 questions) and nurse role-related palliative (4 questions).

Scoring system

Nurse's responses scored as one point for correct answer and zero for an incorrect answer.

Good knowledge if nurses score >75%,

Average if score between 60 to 75%

Poor knowledge if score **<60%**.

Part III: Perception level: it was adapted from **Dehghannezhad et al., 2021**. This section contained 11 items, 5 of which were positive, as nursing care must stretch to the dying person's family, as nursing care for the child's parents must keep going all through the duration of loss and grief, and 6 of which were negative, such as the amount of time it takes to supply nursing care to a dying person will infuriate me, and it is hard to construct a close connection with a member's family.

Scoring system:

For positive items, the Likert scale score ranged from 1 strongly disagree, 2 disagree, 3 strongly agree, 4 agree, 5 to some extent. For negative items, the responses ranged from 1 definitely disagree, 2 disagree, 3 strongly agree, 4 agree, and 5 to some degree.

Greater than 70%, they have a positive attitude. Less than 70%, have a negative attitude.

Methodology:

Preparatory study:

Pilot study A

group of ten nurses took part in a pilot trial (10 percent). It was carried out before data collection to determine the feasibility and duration of the data collection. Because no changes were made, the pilot subjects were incorporated into the research.

Validity: The content's legitimacy was determined by a panel of five pediatric nursing specialists, who were polled on the tools' structure, layout, consistency, correctness, and relevancy.

Reliability: A statistician used Cronbach's alpha coefficient test in SPSS software version 24 to assess the reliability of the customized tools. Internal consistency reliability (Cronbach's) for knowledge level (.0.813) and attitude (.0.813). (.0.849).

Field Work:

The actual fieldwork was carried out for 6 months from early July 2021 up to the end of early January 2022. The researchers were available in the study setting for 2 hours for 2 days/week according to nurses' appropriate time.

The actual fieldwork was divided into four phases:

Assessment phase: (1 month)

During this phase, the investigators used the built tools to gather data on nurses' knowledge and practice in caring for children with terminal illnesses (pre-test). Before beginning interviews and data collection, the investigators described the goal of the investigation and its assumptions to the nurses being researched. Nurses completed the standardized questionnaire form. The time required to complete the questionnaire relied on the nurses' expertise; the mean time varied between 20 and 30 minutes. The investigators completed the monitoring checklist, and the time required to complete the checklist relied on the length of the operation, which varied from 5 to 10 minutes.

Planning phase: (2 months)

After determining the objectives of the program, a discussion with nurses about contents, teaching methods, and evaluation was carried out. The program was designed in light of the literature review and modified to meet the participants' needs. Knowledge and practices were organized and sequenced according to the priority of the nurses and resources needs.

III. Implementation phase: (2 months)

- The studied nurses were divided into 2 major groups and then divided into 5 sub-groups, each group involved 10 nurses. In the beginning, the researcher disseminated the program and informed the nurses how to use the program. The researchers determined 7 sessions for each group in 2 hours within 2 days/ week according to their time allowed for clarifying any misunderstanding in the program or answering any question, sufficient repetitions were done when needed. Each session took 60 - 90 minutes. The total time was 10.5 hours for each group.

IV. Evaluation phase: (1 month)

Following the program's implementation, identical tools were utilized as an indication to estimate the amount of progress.

Ethical Consideration:

Each nurse agreed to participate before participating. The objective of the study was written in the first section of the survey. Additionally, those who volunteered to participate in the study were told that all information gathered would be kept anonymous and that the questionnaire would not contain any personal identifiers. They were told that they could leave the study at any time.

Statistical Analysis:

Using the number and percentage distribution, the acquired data was arranged, updated, marked, tallied, and evaluated. A computer was used to perform a numerical assessment in the social sciences (SPSS). The chi-square test was used to compare qualitative values, while the Pearson connection coefficient was used to compare statistical parameters. The following factors were examined while determining the importance of the findings: When P>0.05, the variation is statistically significant.

Results

Table 1: Distribution of studied nurses according to their characteristics (N=100)

N	%
	39
	49
12	12
22	22
78	78
38	38
32	32
30	30
9	9
71	71
17	17
3	3
	41
_	45
14	14
14	14
86	86
	39 49 12 22 78 38 32 30 9 71 17 3

Table (1) indicates that almost half (49%) of study subjects are between the ages of 30 and 45, with a mean of 37.3 ± 4.9 years. Moreover, three-quarters (78%) of nurses were females. In terms of qualifications, nearly three-quarters of nurses (71%) are graduated from a technical health institute; almost half of the study subjects (45%) have 10 to less than 20 years of experience, with a mean of 12.3 ± 2.87 years. Furthermore, most nurses (86%) lack palliative care training.

Table 2: Comparison between studied nurses' knowledge at pre and postintervention according to palliative care (N=100)

Itoma	Pre		Post		Chi agyana	P-value
Items	N	%	N	%	Chi-square	P-value
Concept of palliative care						
Good	6	6	34	34	12.330	<0.01**
Average	14	14	45	45	12.330	<0.01
Poor	80	80	21	21		
Principle of palliative care						
Good	5	5	38	38		
Average	19	19	50	50	10.909	<0.01**
Poor	76	76	12	12		
Psychological and spiritual						
care	7	7	36	36		
Good	22	22	47	47	12.117	<0.01**
Average	71	71	17	17	12.117	<0.01
Poor	/ 1	/ 1	1 /	1 /		
Management of pain and						
other symptoms:						
Good	5	5	39	39	13.400	<0.01**
Average	28	28	47	47		
Poor	67	67	14	14		
Nurse role-related palliative						
care	8	8	41	41		
Good	26	26	49	49	12.807	<0.01**
Average	66	66	10	10		
Poor	00	00	10	10		

Table (2) illustrates the nurses' knowledge about palliative care before and after an intervention. More than two-thirds of nurses. (67%) had a low level of total knowledge before intervention. Furthermore, nearly a quarter of them (26%) have an average level of knowledge before the intervention, compared to nearly half (49%) after an intervention. , more than one-third (39%) had good knowledge after an intervention. In terms of all recorded characteristics, there is a quantitatively considerable variation between before and after treatment (Chi-square=14.593, p0.01**).

Figure1: Distribution of studied nurses at pre and post-intervention according to total knowledge about palliative care (N=100).

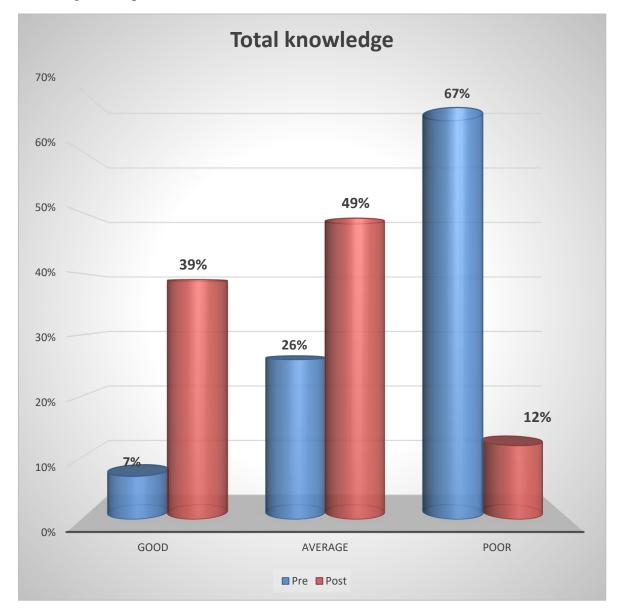


Figure 1. This shows that more than two-thirds of nurses (67%) had a poor level of knowledge before the program intervention, while nearly one-third (39%) had a good level of knowledge after the intervention.

Table 3: Comparison between the means of studied nurses at pre and post-intervention according to their attitude regarding palliative care (N=100)

Items	Pre Mean SD	Post Mean SD	T -test P-value
The length of time required to give nursing care to a dying person would frustrate me	1.98±0.34	3.12±0.47	7.908 <0.01**
It is difficult to form a close relationship with the family of a dying member.	1.76±0.25	3.24 ± 0.43	8.906 <0.01**
Nursing care for the patient's family should continue throughout grief and bereavement	1.01±0.19	3.40 ±0.51	7.999 <0.01**
Nursing care should extend to the family of the dying person	2.10 ±0.28	3.39 ±0.37	9.013 <0.01**
I would be uncomfortable if I entered the room of a terminally ill person and found him/her crying.	1.16±0.18	3.50 ± 0.41	8.117 <0.01**
I am afraid to become friends with chronically sick and dying patients.	1.40±0.20	3.46 ±0.52	7.256 <0.01**
It is beneficial for the chronically sick person to verbalize his/her feelings.	1.27±0.19	3.57 ±0.49	9.664 <0.01**
Palliative care is given only for dying patient	1.33 <u>±</u> 0.36	3.52 ±0.40	8.014 <0.01**
As a patient nears death; the nurse should withdraw from his/her involvement with the patient;	1.20±0.23	3.60 ± 0.38	10.113 <0.01**
You feel psychologically prepared to deal with critical care issues	1.19±0.19	3.64 ±0.52	9.442 <0.01**
Nurses must respect the patient's wishes at this period	1.23±0.15	3.71 ±0.59	8.016 <0.01**

Table 3: This table indicates that prior and after intervention based on the investigated nurses' attitudes about palliative care It demonstrates a very statistically significant difference (p0.01**) between before and post-intervention in all characteristics reported.

Figure 2: Distribution of studied nurses at pre and post-intervention according to total attitude (N=100)

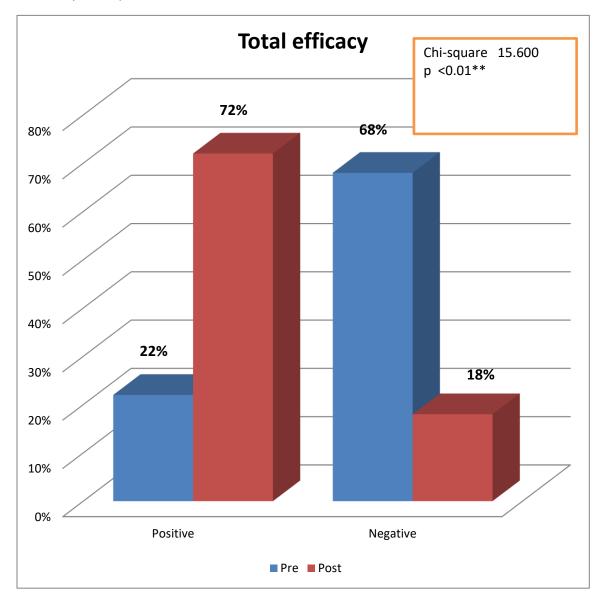


Figure 2: This figure shows that over three-quarters of nurses (72%) have a positive attitude after the intervention, while more than two-thirds (68%) had a negative attitude before intervention.

Total Perception	r.	p. value
knowledge and total attitude pretest	0.657	<0.01**
knowledge and total attitude posttest	0.599	<0.01**

Table (4) Correlation between studied variables pre and post-intervention

Table 4: This table clarifies that there is a highly statistically significant positive relation between total knowledge and total attitude before the test (r = 0.657, p = 0.01**) and Total knowledge and Total attitude after the test (r = 0.599, p = 0.01**).

Discussion

Inadequate palliative care knowledge within nurses is well documented and regarded as one of the biggest challenges to giving exceptional healthcare. One of the most common barriers to providing quality palliative care is nurses' lack of awareness and negative views regarding palliative care. (Chua & Shorey, 2021).

According to the present survey, the average age of the nurses was 37.34.9 years, and more than three-quarters of the nurses were females. In terms of qualifications, less than three-quarters are from a technical health institute. These results are in contrast to the conclusions of the study done by (**Etafa et al., 2020**). In cross-sectional research of 372 nurses operating in local hospitals in Wollega zones, they found that the average age was 29.235.52 and that moreover half of the participants were male.

Furthermore, Al Qadire (2014) revealed that the majority of participants in a cross-sectional study of 190 certified nurses functioning in five Jordanian government hospitals were male and under 30 years old. Before the intervention program, more than two-thirds of nurses had a low level of understanding, according to our study. Moreover, the majority of nurses in this survey demonstrated a lack of awareness of palliative care. One probable explanation is that just a few nurses have

received palliative care training. This finding was similar to findings from earlier research conducted in Florida, California, and India.

Researchers have indeed discovered significant gaps in undergraduate nursing education, as well as in nursing knowledge and attitudes about end-of-life care (**Dobrowolska B, et al,2011**). On the other hand, (**Nepal et al., 2021**) conducted cross-sectional descriptive research amongst 122 nurses, and the study discovered that nurses have a restricted grasp of palliative care but have a good attitude. In addition (**Menekli et al., 2021**). There was a numerically considerable variation in the mean scores of nurses before and after the training program, according to the results (p 0.001). The current study found

that the training program had a significant impact (Cohen's d = 5.540) on nurses' comprehension of palliative care. Likewise, (**Harden et al., 2017**) observed a quantitatively considerable variation in knowledge, attitudes, and behaviors after the educational intervention.

In terms of nurses' attitudes, the present study discovered that more than three-quarters of nurses had a positive attitude after training, whereas more than two-thirds had a negative attitude before training, with an extremely vast improvement at p-value 0.01^{**} . These findings were connected to the use of graphical teaching aids and dependence on simple medical jargon and language, as well as their desire for feedback. These findings are part of a larger group (Hao et al., 2021). The combined intervention was shown to be successful in enhancing participants' knowledge and attitudes toward palliative care. Nurses get training at opportune times during their academic and professional careers. life is vital, particularly to influence participants' views toward death.

Moreover (**Li et al., 2021**). A systematic review approach discovered that palliative care education is an effective tool for enhancing healthcare professionals' and caregivers' knowledge, confidence, and attitudes about palliative care. Furthermore, the mixed-method intervention was found to be successful in enhancing participants' knowledge and attitudes toward palliative care. Furthermore, (**Jiang et al., 2019**). noted that at the moment, Chinese undergraduate nursing students have little awareness about palliative care and the majority have unfavorable opinions toward it. (**White et al., 2021**). The study found that the research helps to understand palliative regarding the current research were statistically significant positive associations between knowledge level and attitude pre and post-training program intervention at p-value 0.01**. These results are consistent with (**Kim et al., 2020**). They conducted cross-sectional descriptive research on 141 nurses and found that nurses' knowledge had a beneficial influence on their degree of attitude toward palliative care. Also, **Acura & Labrague, 2019** It was discovered that raising one's knowledge level increased nurses' attitudes toward palliative care.

Conclusion:

In the light of the present study findings, it can be concluded that pre-developed program disseminated, most of the studied nurses had unsatisfactory perception (knowledge and attitude) related to palliative care toward terminally ill children. Meanwhile, post-program dissemination, nurses' perception (knowledge and attitude) are significantly improved reflects the positive effect of the developing and implementing self-learning program on nurses' perception related to palliative care toward terminally ill children.

Recommendations:

The following recommendations can be suggested depending on the current investigation's findings:

The program which was developed according to the actual need assessment of nurses should be available in all settings that provide care for terminally ill children.

Periodic refreshing training should be provided for all nurses working in intensive care units and better co-operation of health professionals to provide continuous training about the care of terminally ill children.

Periodical revision of training program about terminally ill children, and guide nurses for their perception concerning the care of terminally ill children.

More research should be done to determine the effect of the program at every institution that provides care for terminally ill children.

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الملخص العربي

تأثير برنامج التدريبي على وعي الممرضات تجاه الرعاية التلطيفية للأطفال الذين يعانون من مرض العضال

مقدمة

أن أعداد الأطفال الذين يحتاجون إلى الدعم في المراحل الأخيرة من حياتهم في تزايد مستمر ولذلك أزدادت الرعاية التلطيفية في الرعاية التمريضية. يعد قلة المهارات والمعلومات بين الممرضات من أكثر العوائق انتشارًا للرعاية التلطيفية الممتازة. الهدف من البحث:

تم تصميم هذا البحث لتقييم تأثير برنامج تدريبي على وعي الممرضات تجاه الرعاية التلطيفية للأطفال الذين يعانون من مرض العضال

تصميم البحث: تم إستخدام تصميم شبه تجريبي مكان الدراسة يتم إجراء هذا البحث في أجريت الدراسة في وحدات الغسيل الكلوى ورعاية الحالات الحرجة في مستشفيات الأطفال التابعة لجامعة عين شمس في الفترة من يوليو 2021 حتى يناير 2022 العينة البحثية:

اشتملت عينة البحث (عينة غرضية) على 100 ممرض و ممرضة ممن يقدمون الرعاية التمريضية للأطفال بشكل مباشر في وحدات الغسيل الكلوى ورعاية الحالات الحرجة التابعة لجامعة عين شمس حيث استغرق البحث حوالي 6 أشهر.

أدوات البحث: اشتملت الأدوات المستخدمة في هذه الدراسة ستطبق الأدوات مرتين قبل وبعد التدخل التمريضي علي الأتي:

1. استمارة استبيان تم إعدادها بعد الإطلاع على المراجع العلمية من خلال مقابلة الباحثة مع الممرضات بلغة تتناسب مع المستوى العلمي(1).بيانات شخصية خاصة بالممرضات (السن, المستوى التعليمي, سنوات الخبرة والدورات التدريبية الخاصة بالرعاية التلطيفية...الخ). (2) بيانات خاصة بمعلومات الممرضات تجاة الرعاية التلطيفية للأطفال و(3) بيانات خاصة بالمستوى الأدراكي للممرضات تجاة الرعاية التلطيفية.النتائج: أوضحت نتائج هذه الدراسة ان أكثر من ثلثي الممرضات حوالي (67٪) لديهم مستوى جيد من المعرفة بعد البرنامج التدريبي وأكثر من الثلث (29٪) لديهم مستوى جيد من المعرفة بعد البرنامج التدريبي ، وايضا ، كان هناك علاقة ذو دلالة إحصائية عالية (0.01) في مواقف الممرضات قبل وبعد البرنامج في جميع الجوانب التي تم قياسها. الخلاصة: وجدت هذه الدراسة أن فهم ممرضات الأطفال وممارستهم للرعاية التلطيفية قد تحسن بشكل ملحوظ بعد الانتهاء من برنامج التدريبي . كان هناك أيضًا ارتباط قوي بين معرفة ممرضات الأطفال والمواقف تجاه الرعاية التلطيفية. أخيرًا ، بعد المشاركة في برنامج تدريبي تطبيقي ، تحسنت تصورات ممرضات الأطفال عن الرعاية التلطيفية .

التوصيات: تقديم البرنامج التدريبي للتلطيف والتسكين للأطفال / نهاية العمر كجزء أساسي من روتين العناية التمريضية اليومي، بالإضافة إلى برنامج سريري مستمر لجميع ممرضات الأطفال الذين قد يعتنون بالأطفال المحتضرين