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Development of pain management nursing care program for children with cancer

Abstract

Introduction: Pain management is one of the challenging issues in the paediatric oncologic domain. Strengthening nurses' knowledge and skills are necessary to establish optimal quality of care. The study aimed to develop a pain management nursing care program for children with cancer.

Patients and methods: The participants of the qualitative research phase included 10 children's parents (8 mothers and 2 fathers) and 15 health providers (10 nurses, 3 oncologists, and 2 palliative medicine specialists). The study was the exploratory mixed method according to the Kern model with three phases, including two-stage qualitative stages (literature review and content analysis) in the first phase, providing a draft of the program (Phase 2) and validating the draft, using the Delphi method.

Results: Three main categories emerged from the literature review and qualitative study findings, including factors related to nursing, paediatric parents, and healthcare organizations. They were realized as the base of initial pain management nursing care obstacles that were considered in the program draft. These categories were classified into 3 domains of knowledge, attitude, and skill pain management deficiency. The contents were confirmed in 13 pain management outlines at the Delphi phase. The second phase demonstrated the final program contents, including training on items of pain concept, cancer pain, painful procedures, pain assessment, nursing care, pharmacological and non-pharmacologic interventions as the pillar outlines in pain management.

Conclusions: The nursing care pain management program in children with cancer with an innovative view provides professional educational opportunities for optimal pain management.

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Key words: children with cancer, nursing care, pain management program

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Introduction

Pain management in children with cancer is a challenging issue that leaves unpleasant memories associated with tissue damage in children's experiences. As an intellectual phenomenon, children cannot express their affliction through verbal communication. This issue adversely affects their physical and physiological conditions, including insomnia, anorexia, fear, anxiety, helplessness, and refusal to continue the care process [1]. Ineffective pain management is still a typical subject in paediatric care systems. Hence, most children experience moderate to severe pain in hospitals. Unconsciousness of the health care providers, especially nurses, as a key element of the caring process intensifies the problem. Improper attitudes, knowledge, and skills originate from inadequate training in pain management methods. Unawareness about pain assessment tools, ineffective communication with families, and reliance on personal judgments instead of standard performance according to evidence-based sources are the factors that lead to a defective cycle [2]. Gaining ideal nursing pain management depends on the interactive position between the physician's decision and the nurses' intervention. It must be perceived as a central concept in the nursing process, including pain diagnosis, assessment, planning, implementation, and evaluation phases. On the other hand, respecting the children's rights for an optimal experience of convenience in the caring process is a neglected health issue that needs to be retrieved for effective outcomes [3, 4].

Pain management is also a central part of cancer treatment. Cancer as a modern chronic disease is rising with a prevalence of approximately 15 per 100,000 people worldwide. In the United States, about one in 285 children is diagnosed with cancer before age 20. In Iran, about 4% of children under five years of age and 13% of deaths of children aged 5–10 years are engaged with cancer. Due to the invasive nature of the disease and unpredicted outcomes, children and their parents experience high levels of unexpected anxiety. Children suffer from pain frequently during therapies which raises parents' hopelessness and anxiety. Hence, effective pain management is integral to cancer care that improves treatment [5, 6].

In Iran, pain management is implemented according to physician prescriptions. The dynamic nursing pain management assessment, planning, and intervention are missed in medical protocols, so the expected outcomes of effective pain management are not evident in patients. Smeland et al. [2] study indicated that despite pain management guidelines, nurses do not function adequately according to evidence; hence, it is

vital to strengthen nurses' awareness and performance in pain management by continuing education [2]. Previous studies also demonstrated that nurses inadequately manage pain, and the priority of care is on cancer treatment and control of the invasive nature of the disease [5–8]. Further, it is required to frequently focus on pain management as a missed nursing diagnosis in the health system. Strengthening nurses' knowledge and skills are necessary to establish optimal quality of care. Accordingly, the current study aimed to develop a pain management nursing care program for children with cancer.

Participants and methods

Participants

The participants of the qualitative research phase included 10 children's parents (8 mothers and 2 fathers) and 15 health providers (10 nurses, 3 oncologists, and 2 palliative medicine specialists). The participants were the health providers of cancer hospitals affiliated with Isfahan University of Medical Sciences. They were selected by the purposive sampling method with maximum variations in gender, age, and educational levels [9]. The general characteristic of participants is shown in Table 1.

Methods

The study has three main phases: the literature review and qualitative part as the first phase, providing a draft of the program, and the Delphi method as the final phase. The process was designed according to the kern model, including oncologic health providers' and parents' exploration views, providing the draft, validating, and confirming the program. In the qualitative phase, the researchers attempted to engage with pain management events in the clinical field through a closed engagement in the paediatric oncology ward for five months with an interactive relationship with the children and their parents. The interviews were organized throughout this period. To enhance trustworthiness in the qualitative phase, consideration of maximum variations in participant selection, including parents, nurses, and physicians, were considered. The qualitative findings were based on the provision of the initial draft of the program in the second phase. Finally, the Delphi method was conducted as the validation phase to confirm program contents from experts' views. The study design is shown in Figure 1. The Ethics Committee of Isfahan University of Medical Sciences approved the study (IR.MUI.NUREMA.REC.1400.137 code). Ethical principles such as informed consent, autonomy, privacy, confidentiality, and voluntary participation were considered too.

Table 1. General characteristics of participants

Characteristics of participant	Parents		Health provider	
	Number/percentage		Number/percentage	
Age range				
• 30–45	3	12%	10	40%
• 46–60	7	28%	5	20%
Sex				
• Male	2	8%	5	20%
• Female	8	32%	10	40%
Marital status				
• Married	10	40%	12	48%
• Single	0	0	3	12%
Educational level				
• Under diploma	2	8%	0	0
• Diploma	3	12%	0	0
• BSc	5	20%	3	12%
• MSc	0	0	5	20%
• PhD	0	0	5	20%
• Professor	0	0	2	8%

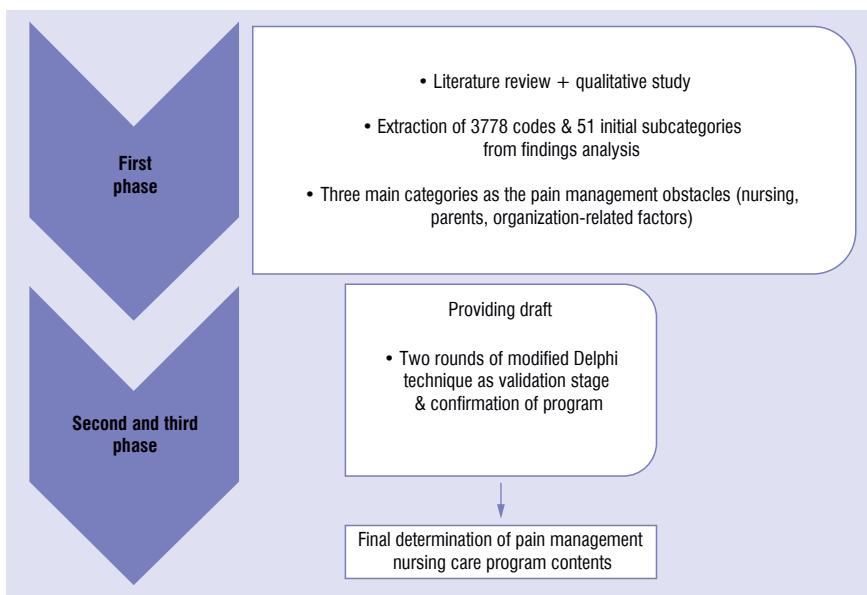


Figure 1. Overview of the study design

Phase 1

Stage 1: Literature review

A literature review was conducted by searching several databases, including Medline, ProQuest, ISI Web of Science, ScienceDirect, and Scopus. The search keywords were “Pain management”, “Program”, “Children with cancer,” and “nursing care”. The studies were selected from the current six years (2015–2021) to examine the newest evidence. Moreover, searching SID, SCI, and Magiran databases with English keywords was conducted to explore Persian texts. Afterwards, duplicate studies, letters to the editor, posters, and conference papers were excluded from the review to

attain original articles on pain management. Finally, 72 studies were included in the review process.

Stage 2: Qualitative study (Investigating the needs)

The qualitative research was conducted through in-depth interviews with health providers and parents parallel to the literature review to explore pain management requirements. The analysis of findings was demonstrated after the third interview. The code extraction of codes, concepts, and organization of categories continued to data saturation that no new data emerged.

Table 2. Category and subcategories of nursing-related factors

Codes	Subcategory	Main Category
Low attention to providing painless conditions for children	Attitude weakness	Nursing-related factors
Restriction to do independently in pain management		
Parents exaggerate to use of painkillers		
Concerns about analgesic side effects		
Concerns about drug dependency		
Weak support from nurses' leaders		
Weak intimate atmosphere between nurses and parents in a painful situation		
Weak participation with parents in pain management	Functional weakness	
Weak practical skills in working on pain assessment scales		
Unserious planning		
High anxiety in outbreaks of pain conditions	Knowledge weakness	
Inadequate information about pain management		
Unawareness of cancer pain		
Insufficient educational study		

Setting

The study was conducted in the Paediatric Oncology Department and Palliative Medicine Centre of Seyed Al-Shohada Hospital, the main centre of paediatric cancer care services in Isfahan.

Inclusion and exclusion criteria

The participants in the qualitative phase were selected among healthcare providers with at least 6 months of work experience in the paediatric oncology department. The parents also were the children's caregivers in the unit during the treatment process. The children weren't considered for the interview process because the parents were worried about their children's offence to disease. A tendency to participate in the study and fluency in the Persian language were the other inclusion criteria for parents and health providers. The study's aims were explained to the participants before filling out the consent, and they had the right to withdraw at any stage.

Qualitative data collection method

In this phase, the data were collected using in-depth semi-structured interviews concurrent with field note-taking and observation. The place and duration of interviews were conducted based on the participants' preferences. The first and corresponding authors conducted 30 interviews with 25 participants, averaging 15 minutes. The interviews continued until data saturation.

Interview questions

The interview questions were designed according to the viewpoints of parents and healthcare providers. The researcher started with general questions such as "Talk about your experiences in pain management. How is it?" Then, the probing questions were asked to clarify the participants' viewpoints. At the end of each interview, the researcher summarized the participants' discussions to ensure content trustworthiness.

Analysis of qualitative data

The interviews were typed into Microsoft Word Office Software, word by word, and data were analysed by the conventional content analysis method according to Granheim and Lundman method. In addition, Guba and Lincoln's criteria of credibility, dependability, transferability, and confirmability were considered to obtain the trustworthiness of the findings. Two authors (the first and corresponding author) were involved in data collection and analysis to ensure credibility. The coding process and categorizing were conducted through constant comparison of related findings. The second author, the qualitative nursing master, reviewed the analysis process. Moreover, nurses, physicians, and parents as various participants, in-depth interviews, and continuous presence in paediatric oncology wards were the researchers' interventions to obtain the study's rigour. Tables 2, 3 and 4 provide the results of the study's first phase.

Table 3. Category of children's parent-related factors

Parents' reluctance to use painkillers for their pediatrics' pain management	Attitude weakness	Children parent-related factors
Concern about analgesic side effects		
Concerns about drug dependency & addiction	Functional weakness	
Insufficient reciprocal communication between nurses and parents		
Parents' unwillingness to be present during painful procedures		
Weak parents' performance in working by simple pain assessment scales		
Weak parents function according to nursing education		
High anxiety during the severe child pain		
Inadequate parents' information about non-pharmacological pain management	Knowledge weakness	

Table 4. Organization-related factors

Weak priority in health systems	Attitude weakness	Organization related factors
Unserious about children's rights in pain management		
High work pressure on nurses	Functional weakness	
I am not considering unique places inwards for painful procedures		
Weak supervision in pain management		
Weak attention to pain as the nursing continuing education programs		

Phase II and III: Providing draft and validation of program contents

According to qualitative and literature review findings, the initial draft of program contents was provided in this phase. The draft was emailed to oncologic experts to determine the priority of items by two rounds of the modified Delphi technique.

Modified Delphi technique

In the validation phase, 2 paediatric cancer experts, who were faculty members of Isfahan University of Medical Sciences, examined the initial program contents. Afterwards, the researchers emailed the draft to 14 oncologic experts, including 8 PhD nurses with experience in paediatric cancer and 6 oncologists who were faculty members of Tehran and Isfahan Universities of Medical Sciences. The Delphi questionnaires for evaluation of the draft were generated according to two dimensions acceptance and the priority of items. The experts must grade the items by Likert scoring. (1: weak item, 2: acceptable, 3: good, 4: excellent). In addition, an open question was placed in the draft for the experts to add extra items if they had any comments. After one week, the experts were reminded to return the results. Afterwards, the researchers examined the collected questionnaires and data by IBM SPSS software, version 20 analysis. The acceptance and priorities of the items were determined by the highest mean in SPSS results. The items with the lower mean report were discussed

to revise again, and the necessary corrections to the contents were conducted. The new items were added to the revised questionnaire according to experts' considerations, including aesthetic, ethical, spiritual, and therapeutic communication issues. The questionnaire was emailed again to previous experts for the second round of Delphi to grade again. The Delphi questionnaire analysis is displayed in Table 5. The second Delphi method results were the base of the final pain management nursing care program contents. Notably, parents didn't participate directly in the Delphi methods, but the researchers provided simple outlines of the program and contribute it to parents to reflect their comments to the researchers [9]. The method description is shown in Figure 2.

Results

Qualitative phase findings

Three main categories emerged from the literature review and qualitative study findings, including factors related to nursing, paediatric parents, and healthcare organizations. These categories were classified into 3 domains of knowledge, attitude, and skill pain management deficiency. The results of the first phase are summarized in Tables 2 and 4.

Nursing-related factors

Nurses' competency is an essential element in pain management. The nurses don't have sufficient

Table 5. Delphi questionnaire analysis

Questioner items	Round 1	Round 2
	Mean	Mean
Pain concept	2.84	3.0
Cancer pain	2.78	3.0
Painful procedure	2.70	2.98
WHO ladder	2.67	2.92
Pain assessment	2.64	2.91
Nursing care	2.55	2.90
Pharmacologic intervention	2.44	2.88
Non pharmacologic intervention	2.30	2.82
Ethical issues in pain management	2.27	2.77
Parents empowerment	2.19	2.75
Therapeutic communication	2.16	2.71
Spiritual care	2.13	2.70
Aesthetic in pain management	2.05	2.70

WHO — World Health Organization

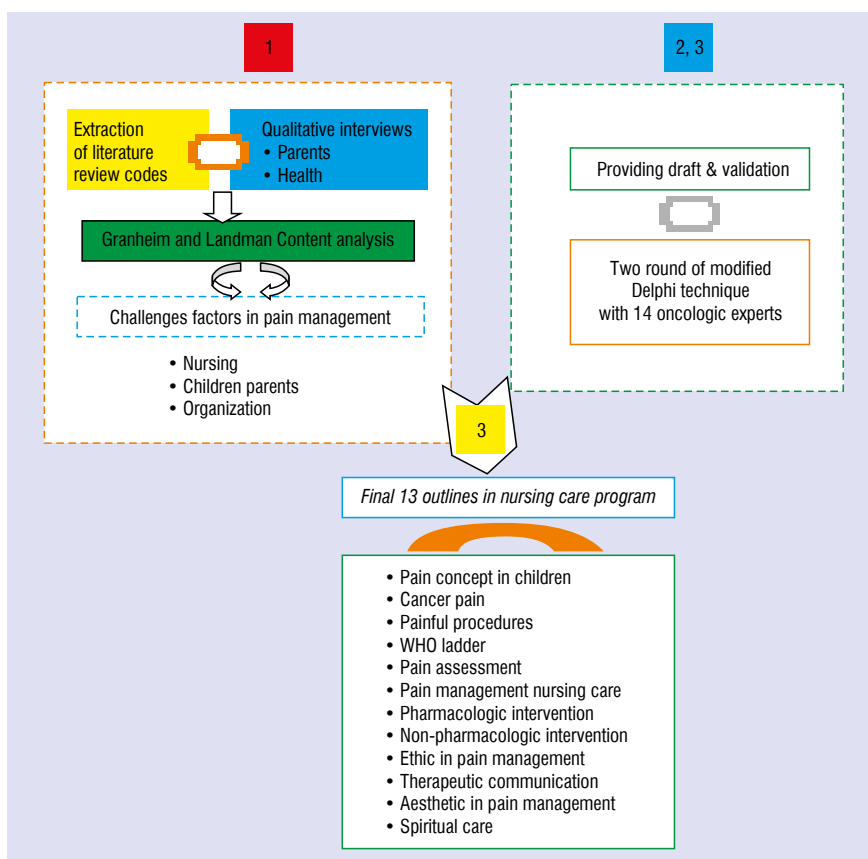


Figure 2. Method description; WHO — World Health Organization

practical skills, attitudes, and authority to independently program pain management planning.

"I think, parents usually exaggerate their children's pain while the children don't comprehend pain like adults" (Nurse 5).

"I don't know about different pain assessment scales. I say to my patient, describe your pain by one to ten grades" (Nurse 3).

"We don't have any authority to manage child pain. We must have the physician's order for any intervention, and it is a big problem in pain management" (Nurse 2).

Parent-relating factors

The parents are the principal agent in the children's treatment process. The obstacles that prevent effective pain management are concerns about analgesic side effects, reluctance to present during painful procedures and unawareness of pain management methods.

"We prefer to avoid painkillers in our family as possible as; everyone knows that hospital analgesics cause drug dependency and create continuing addiction to opium for pain relief" (Father 2).

"I can't tolerate my child's pain during needle insertion, the nurses made me upset to say be present at your child's bedside, but I prefer to go out of the room" (Mother 1).

"The nurses usually do easy way in pain relief; they give me warm pack. My child needs a doctor visit. Warm pack doesn't have any effect on cancer pain" (Mother 3).

Organization-related factors

The organizational policy is inevitably essential in confirming the quality of care and providing a positive atmosphere for effective pain management in the health system.

"Effective pain management needs enough nursing personnel; the nurse can't work effectively when the system doesn't pay attention to provide sufficient human resources" (Nurse 5).

"Pain management education for the health providers is not the priority in the system. I received patients' complaints about improper pain management daily. It seems as the primary issue, but it needs to train frequently by continuing education programs" (Oncologist 2).

"Everything relies on system supervision. I think we can improve our care quality by system support and strong supervision" (Palliative medicine specialist 1).

Results of the second phase

Delphi method results as the validation phase confirmed the final outlines of program contents in thirteen outlines, including pain concept in children, cancer pain, common painful procedures, WHO pain management

ladder, pain assessment, nursing care in pain management, pharmacologic interventions, nonpharmacologic interventions were confirmed as the inevitable items in the pain management program and additional items including ethics in pain management, empowerment of parents, therapeutic communications, spiritual care in cancer pain and aesthetic in pain management were confirmed as new concepts (Table 6, Fig. 3).

Discussion

Nurses, as one of the key elements of the health care system, have a critical role in paediatric cancer pain management. The nurses' knowledge, attitudes, and skills reinforcement are essential factors in this issue. This study aimed to develop a nursing care pain management program based on the novel views of stakeholders and existing evidence. Three categories of obstacles were reported in the qualitative phase: nursing-, parent- and organization-related factors. Nurses' incompetency to manage pain effectively according to standard criteria, misconceptions about children's pain, and dependency on physicians' prescriptions are the significant factors that intensify improper child cancer pain management. Some studies emphasized that nurses' training is the solution. Continuing education and revising their attitude about pain concepts are the priorities for ideal performance [2–4].

Parent-related factors are the other obstacles to effective cancer pain management. Parents' concerns about opium addiction, the side effects of analgesic drugs, their reluctance to be present in painful situations, and the underestimation of non-pharmacological methods were the factors that lead to ineffective cancer pain management. Parents' empowerment by continuing nurse training is the main element in increasing their attitudes and participation in the care process [4, 10]. Organizational support is another essential factor that guarantees the quality of cancer pain management. Continued supervision, provision of facilitation, and supporting the system are crucial factors for effective pain management [4, 11].

The findings of the study's second phase demonstrated the final program contents, including training on items of pain concept, cancer pain, painful procedures, pain assessment, nursing care, and pharmacological and non-pharmacologic interventions as the pillar outlines in pain management. The study revealed some hidden and novel items in pain management too. Other concepts include ethical issues, parents' empowerment, therapeutic communication, spiritual care, and aesthetics in pain management. The synergistic combination of reinforcement of nurses' knowledge, attitudes, and skills according to attained

Table 6. Outlines of the pain management nursing care program (*New views)

<p>1. Pain concept in children</p> <ul style="list-style-type: none"> • Mechanism • Anatomy • Physiology • Symptoms • Outcomes
<p>2. Cancer pain</p> <ul style="list-style-type: none"> • Types of cancer pain • Reasons • Features • Resistance pain • PCA
<p>3. Common painful procedures</p> <ul style="list-style-type: none"> • Radiation therapy • Chemotherapy • Bone marrow biopsy • Transplantation • Invasive treatment
<p>4. WHO pain management ladder Level of intervention in</p> <ul style="list-style-type: none"> • Mild • Moderate • Severe and persistent pain
<p>5. Pain assessment</p> <ul style="list-style-type: none"> • History taking • Determination of the severity of the pain • Method of working with a pain scale
<p>6. Nursing care in pain management</p> <ul style="list-style-type: none"> • Diagnosis of kind of pain • Precise assess • Intervention • Evaluation • Documentation
<p>7. Pharmacologic intervention</p> <ul style="list-style-type: none"> • Analgesic and opium • Dependency and addiction • Side effects • Consideration
<p>8. Non-pharmacologic intervention</p> <ul style="list-style-type: none"> • Physical intervention • Phycological intervention • Recognitional intervention • Playing therapy
<p>9. Ethics in pain management*</p> <ul style="list-style-type: none"> • Placebo • Cultural respect
<p>10. Empowerment of parents*</p> <ul style="list-style-type: none"> • Education • Participation • Support
<p>11. Therapeutic communication*</p> <ul style="list-style-type: none"> • Reciprocal trust • Family priority consideration • Parents treatment engagement • Intimacy
<p>12. Spiritual care in cancer pain*</p> <ul style="list-style-type: none"> • Respect to faith needs • Provision of convenient painless conditions • Continues presence of the child's family
<p>13. Aesthetic in pain management*</p> <ul style="list-style-type: none"> • Art in caring • Beautiful unit design • Special architect for the invasive procedure place

PCA — patient-controlled analgesia; WHO — World Health Organization

outlines with intimate relationships and team working between physicians and nurses will eliminate the barriers gradually and improve pain management conditions in children with cancer [12–14]. On the other hand, respecting parents’ concerns and perusing them to participate in the caring process is the other integral part of the effective pain management cycle. The nurses should have a constant and close relationship with children and their parents, which lead to optimal outcomes [4, 10, 15].

The novel items from this study demonstrated innovative views about pain management. Spiritual care in cancer pain is one of the emerging concepts. Human beings need spiritual support to deal with unpleasant events such as pain. The reinforcement of spiritual power decreases the negative intensive pressures of difficulties and increases satisfaction and hope in the face of diseases. Spiritual care is the basis for awakening and simulating this power. Consideration of spiritual care as an integral part of the pain management program can heal the children’s annoyance during the treatment process. Notably, this is a missed concept in other studies. Therefore, it is recommended that future studies investigate nurses’ and parents’ views on spiritual care’s effect on pain management [16]. The aesthetic issues in pain management were another novel item in the program. It is implied that pain management is an art in nursing science. Music therapy and attractive architecture in oncologic paediatric departments create a calm atmosphere in the children. The aesthetic sense encourages the children to modify their negative emotions by painting and playing with toys. In this regard, it is suggested to investigate aesthetic strategies to improve painful conditions [17].

Therapeutic communication and parents’ empowerment in the caring process were the other novel concepts in this study. The intimate relationship between patients and health providers assists in shaping therapeutic communication that removes the interpersonal obstacles in pain management [18]. Overall, the nursing care pain management program is one of the essentials for obtaining optimal outcomes in paediatric oncologic wards. Teamworking, interdisciplinary cooperation between nurses and physicians, participation of parents in the caring process, and organizational support are the other ingredients that led to success in obtaining effective pain management [18–22]. The study findings are helpful for policymakers to consider new dimensions in paediatric palliative care. According to the novel program, nurses’ education led to reconsidering the traditional protocol and new nursing care intervention plans in the clinical setting.



Figure 3. Pain management nursing care program contents

Study limitations

This study investigated the new lens in pain management nursing care. It was some limitations too. First, the study wasn't included the implementation phase. Thus, designing an implementation and evaluation phase is suggested to examine the program's effectiveness. Further, it was necessary to prevent parents' concerns about their children's caring situation, so the children's interviews were omitted from the study. The fathers' number for interviews was limited because the mothers were almost present in the hospital as caregivers. It is suggested to design studies considering fathers' and children's viewpoints. The parents didn't participate in the Delphi phase, directly. It is suggested to involve parents as a target group in future studies.

Conclusions

Pain management nursing care in children with cancer is challenging in the health care system. Reinforcement of nurses' knowledge, attitudes, and practical skills are essential to efficient optimal pain management. Developing a pain management nursing care program is one of the vital steps in strengthening nurses' competencies. The current study's findings provide the basis to revise the protocols and consi-

der a novel lens in pain management nursing care. Planning practical professional nursing continuing education modules can improve effective pain management in children with cancer.

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Declaration of conflict of interest

The authors declare that there is no conflict of interest.

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