
PAIN SELF MANAGEMENT OF CANCER PATIENTS: A DESCRIPTIVE STUDY ON CHILDREN WITH CANCER

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ABSTRACT

Pain is a common symptom that is reported as moderate to severe among children with cancer. The aim of this study was to describe about the pain knowledge related to pain self-management and adherence to pain treatment among children with cancer. By using quantitative research design and description analytically, this research was conducted on 36 children and adolescent in a Community Foundation for the Children and Adolescent with Cancer in Padang City, West Sumatra. Children were given a questionnaire adopted from the NOC (Nursing Outcome Classification) regarding knowledge of pain self-management. Data analysis uses descriptive analysis to capture a perception of each statement point in the questionnaire. The results of this study showed that there are still 33.3% and 25% of children and adolescents who have a lack of knowledge in pain in self-management. Lack of knowledge in children with cancer will influence the way of handling pain. This study shows the knowledge of children and adolescents regarding pain management, where many of them still do not know the appropriate pain management options to use. It is hoped that parents and health care providers can be more active in providing education regarding pain management, so that it can indirectly improve the quality of life of children with cancer.

Keywords: *Pain, self-management, cancer, children*

INTRODUCTION

Pain is such a common and continuous symptom that happens during every condition of disease stages among children with cancer. It reported as a moderate to severe pain by their parents (Tutelman et al., 2018). A study said that the most usual common symptoms experienced by children and adolescents with cancer are depression, anxiety, pain during some procedures taken and some treatment, nausea and fatigue, and also sleep disturbance (Yu.A, 2024). The most common symptoms of cancer among children with prevalence in

range more than 35% of them were lack of energy, pain, nausea, cough, and psychological symptoms (feeling nervous, sad, worrying and also irritable feelings) (Collins et al., 2000). By increasing knowledge about pain management among children with cancer, will help us to reduce their pain and will allow us to meet the needs of children and parents on their pain self-management (Ljungman et al., 2000).

Some of the changes that occur during the therapy program will cause children with cancer to spend more time at home (Fortier et

al., 2011) so this makes the family increasingly responsible for managing the pain experience among their children (James et al., 2002). Studies on home pain management reveal parental misunderstandings, where parents believe that cancer pain is unavoidable and they lead to the use of addictive analgesics (Fortier et al., 2012). A previous study stated that children (1-18 years) who received outpatient chemotherapy, would report clinically significant pain events at home in the absence of medication (Simon et al., 2020). Although there are effective pain intervention options (either pharmacological or non-pharmacological) for children with cancer, parents tend to underestimate pain (Fortier et al., 2014). The pain felt will affect the quality of life of cancer sufferers and this condition of continuous pain must be managed (Sung, 2015).

The most common etiology of this pain among children with cancer is chemotherapy and some invasive procedural while the pain comes with the disease itself. Pain self-management was needed to reduce the severity of the pain level. Cancer therapy with high-intensity chemotherapy is a significant causal factor in the frequency of patient pain (Fortier et al., 2014). There are two categories that emerged from several studies about pain self-management in children, through psychological and behavioral pain self-management strategies. Psychological approaches usually taken were pain distraction therapy; spiritual tendencies, increasing social interactions and support system and networking, pain tolerance and self-control, and resistance to pain. Behavioral strategies included massage and touch, heat and cold therapy, herbal and home remedies, and proper diet (Orujlu et al., 2023).

Several studies have begun to explore the subjective experience of pediatric pain and children's ability to report their pain

experiences during chronic pain (Pope et al., 2015). Even though there has been an increase in knowledge and guidelines for managing pain, it is widely known among teenagers, but the experience of pain management felt on a scale of moderate to severe pain is still common in children who are hospitalized with suboptimal analgesic administration. Children and adolescents have the right to appropriate pain management care (Birnie et al., 2014). Chronic pain in children and adolescents can be difficult to handle by caregivers, in this case parents or family. Part of this difficulty is that chronic pain in school-aged children through to teenagers not only impacts the child but also impacts the families of those children. A multidisciplinary approach to managing children with severe chronic pain conditions is needed, including pediatric pain rehabilitation programs are also emphasized. In addition, pain management is also needed in psychological factors and interventions for pediatric chronic pain and the potential for complementary and alternative natural products and interventions (Landry et al., 2015).

Pharmacological treatment is part of a complementary and comprehensive treatment approach; however, it is important to assess and evaluate pain before deciding what pharmacological or non-pharmacological therapy to use in pain management. In the term of chronic pain management, non-pharmacological interventions have a very important role, but without overriding pharmacological therapy (Friedrichsdorf & Goubert, 2020). It is important for parents and health care providers to provide knowledge about children's pain experiences. There are studies that reveal gaps in children's self-reported pain at rest and during movement (Vejzovic et al., 2020). The purpose of this study is to describe the pain knowledge related to pain self-management and adherence to pain treatment among children



with cancer. Furthermore, this research was to have a description of the self-statements of children with cancer about what they have done to reduce and manage their pain. How they manage pain and the extent of their knowledge regarding this matter. It was such new research regarding the measurements and instruments used using standard outcome indicators from the NOC which can broadly cover many statements related to pain management in children, especially in managing pain due to the cancer they suffer from.

METHODS

Research design

This research uses a quantitative research design with a descriptive analytical approach which aims to analyze pain self-management in children and adolescents suffering from cancer.

Samples and Setting

This research took a sample of 36 adolescent respondents who were in the shelter of the “Yayasan Komunitas Cahaya” as a Community Foundation for the Children and Adolescent with Cancer in Padang City, West Sumatra. This research was conducted in mid-August to September 2024. Samples were taken using accidental sampling, with inclusion criteria; a children and adolescent patients with cancer, children aged as a school age rate until adolescent, children with cancer diagnosed and undergoing treatment with parents or caregivers as a support system.

Research Instrument

The instrument used was a modified questionnaire regarding knowledge: pain management which was taken based on the Nursing Outcomes Classification (Moorhead et al., 2013) assessment instrument and several questions related to self-management

in carrying out pain control and pain management in children. The total number of questions is 17 positive statement items using a Likert scale with the following ratings: "Don't know" is rated 1, "Knows enough" is rated 2, "Knows" is rated 3, and "Very knowledgeable" is rated 4. Validity and reliability test results from the questionnaire This has been measured with valid results of 0.357 to 0.792 and a $r=0.897$. In this study, the cronbach alpha ranged from 0.866 to 0.894 according to the reliability test.

Data Analysis

The data analysis used descriptive frequency to see a description of the pain self-management variable for children and adolescent patients with cancer.

Research Ethics

This study has obtained ethical approval with Number: 289/KEPK/VIII/2024. This study was also conducted by following ethical principles by maintaining confidentiality and providing *informed consent* before starting treatment on all respondents.

RESULTS

Descriptive analysis was carried out to describe the characteristics of respondents (Table 1) and research variables which will be presented in the form of a frequency distribution table. In this study, Descriptive analysis will describe the categories of knowledge of children and adolescents regarding self-management and pain management.

Based on the frequency distribution Table 1, of the 36 respondents, the average age of teenagers was 14.13 (SD=0.689). Most respondents were male (69.4%) with the most common type of cancer being ALL Leukemia (30.6%).



Table 1. Characteristics of Respondents (N=36)

Variable	Mean (SD)	f	%
Age	14.13 (0.689)		
Pain Level	5.78 (0.975)		
Gender			
Man		25	69.4
Woman		11	30.6
Types of Cancer			
Leukemia AML		6	16.7
ALL Leukemia		11	30.6
Retinoblastoma		3	8.2
Synovial Sarcoma		5	13.9
Ewing's sarcoma (SE)		6	16.7
Primitive Neuroectdermal Tumor (PNET)		5	13.9
Stage of Cancer			
Stage 1		7	19.5
Stage 2		5	13.9
Stage 3		9	16.7
Unknown		14	38.9
Time of suffering from cancer			
More than 5 years		9	25
Less than 5 years		27	75
Caregivers			
Parents		30	83.3
Other family members		6	16.7
Get a prescription for pain medication			
Yes		28	77.7
No		8	22.3
Under chemotherapy			
Yes		30	83.3
No		6	16.7
Pain management (non-pharmacological)			
Knowing Enough		16	44.4
Not Know		12	33.3
Understand Well		8	22.3
Knowledge of Controlling Pain			
Knowing Enough		19	52.7
Not Know		9	25
Understand Well		8	22.3



The average respondent was in stage 3, with the caregivers mostly being parents (83.3%). The respondent was also recorded as undergoing chemotherapy and receiving pain-reducing medication. Most teenagers'

knowledge of pain management regarding non-pharmacological pain management is known enough (44.4%), and as many as 52.7% of teenagers know enough regarding strategies to control the pain they feel.

Table 2. Frequency Distribution of Characteristics and Categories of Pain Self-Management of Children with Cancer Based on Questionnaire (N=36)

Variables	Mean (SD)	Min-Max	a*
Factors causing pain	1.95 (1.119)	1-4	11
Signs and symptoms of pain	2.12 (1.1136)	1-4	5
Strategies for controlling pain	2.02 (1.157)	1-4	9
Strategies for managing chronic pain	1.39 (0.835)	1-4	17
How to use prescribed medication safely	2.38 (1.198)	1-4	2
Drug side effects	2.01 (1.155)	1-4	10
Correct storage of medicines	2.58 (1.195)	1-4	1
The importance of adherence to drug regimens	2.03 (1.143)	1-4	7
The importance of informing healthcare professionals about current medications	2.03 (1.122)	1-4	8
Pain management techniques (non-pharmacological)	1.82 (1.072)	1-4	13
Deep breathing relaxation technique	1.81 (1.097)	1-4	14
Benefits of relaxation techniques	1.87 (1.092)	1-4	12
Other pain management techniques	1.50 (0.841)	1-4	16
Hypnocommunication therapy	2.15 (1.138)	1-4	4
Guided Imagery therapy	2.37 (1.223)	1-4	3
Musical/Murrotal therapy	2.11 (1.121)	1-4	6
Parents supporting pain therapy	1.56 (0.877)	1-4	15

*a = rank of variable

Based on the table above, it is known that teenagers already have good knowledge of pharmacological and non-pharmacological pain management techniques. In managing pharmacological pain, adolescents know the most about how to store medication correctly with a mean of 2.58 (SD=1.195). The most common non-pharmacological pain management used by teenagers is massage/acupressure techniques, hypnocommunication and guided imagery as well as murrotal and music therapy. Meanwhile, adolescents answered that they

least knew about strategies for managing chronic pain with a mean of 1.39 (SD=0.835).

DISCUSSION

In a descriptive study of pain management experiences carried out by teenagers who stated that they experienced pain, reporting moderate to severe pain when chronic pain occurred (Pope et al., 2015). Undertreated of pain can bring the worst situation in every aspect of life, its resulting in both physiological and psychosocial (McNeill et al., 2004). Acute Lymphoblastic Leukemia (ALL) is one of Leukemia types of cancer



leukocytes where malignant proliferation of lymphoblast cells occurs. Clinical symptoms generally include fever, pallor, lack of appetite, weight loss, malaise, fatigue, bone and joint pain, epistaxis and tendency to bleed, susceptibility to infection, and headaches. The incidence of ALL in Indonesia is still very high and is the type of cancer that occurs most often and causes death in children, so it is necessary to conduct research on the characteristics of acute lymphoblastic leukemia patients. This study reported the most common type of cancer being ALL Leukemia (30.6%) as a third stage (16.7%) that suffers man the most (69.4%). A study said that Most ALL sufferers fall into the age group <15 years, which is 49 people (53.26%), diagnosed and 60.78% of them are men (Silva et al., 2017).

On this study, we have reached the data about more of the participants did not know about the stadium of their cancer (38.9%) both children and parents or another caregiver. There are more 70-80% young women cannot understand about cancer stadium as abreast early cancer detection. They have lack of knowledge about this type of cancer and they have been known on advanced stage of this disease (Wijayanti et al., 2020). Most of the participants have been suffering from cancer for less than five years (75%) so that it can affect the knowledge about pain management. Experience has a main criteria of controlling for the symptom severity on pain, older patients were more likely to be in the Higher or Medium Suffering profile than in the Low Suffering profile; no other socio-demographic or clinical variables had a significant effect on the latent profile classification (Weaver et al., 2022). Then the most therapy was using chemotherapy. This is a main treatment for cancer patients, even for children. Medicine can help with the worst prognosis for the patients. Progress in medicine has increased

the survival time of children suffering from cancer; >80% of patients survive for at least 5 years from the end of treatment. However, there are late effects of anticancer therapy, which accompany this success (Kruseova et al., 2023).

Parents were the most common caregivers found in this study (83.3%). Education for parents as caregivers or those caring for children with cancer is one of the important things to be concerned. Nurses play an important role in providing explanations regarding conditions, avoiding complications, providing quality services, increasing adherence to treatment and maintaining basic standards of care. Carrying out an assessment of parents' needs will increase knowledge and success in achieving children's pain self-management at home (Hilario et al., 2023). Children with cancer tend to receive more intense treatment therapy, one of which is chemotherapy as well. In this study, 83.3% of children undergo chemotherapy. Post-chemotherapy discomfort is often reported by parents. This discomfort takes the form of physical disorders such as pain, nausea, vomiting and sleep disturbances. This condition requires sensitivity from caregivers, especially parents (Meryk et al., 2022).

This study shows that there are still children who do not know how to control pain. The role of caregivers and nurses is important in helping children describe pain so they can control it. By controlling the experience of symptom severity, it is hoped that children will be better able to carry out daily activities without the need for tantrum sessions. Caregiver and nurse knowledge of the strong relationship between fatigue, child tantrums and pain, and the severity of anxiety can help focus supportive care to improve the cancer experience for children under medication most at risk from diagnosis to treatment (Weaver et al., 2022).



In terms of oncology treatment in children, pain management is always becoming a challenging practical problem. Nurses must first be equipped with standard knowledge, attitudes and skills related to pain management. This research aims to develop a pain management nursing care program for children with cancer. A study reported that there are 3 main categories of basic needs in managing pain in children with cancer. The three main categories are factors related to nursing, the child's parents as caregivers, and health service organizations in pain management. The development of a pain management nursing care program for nurses will provide professional educational opportunities for optimal pain management in children with cancer (Naseri et al., 2024). Pain management both practically uses pharmacological and non-pharmacological treatment.

In treating pain on the non-pharmacological therapy, a retrospective study was conducted on the use of non-pharmacological methods among adolescents to overcome their pain. Ninety-eight percent of adolescents reported using at least one non-pharmacological method (eg, warm compresses or relaxation therapy to manage their pain. It is possible that some methods are used because they have a physiological impact on pain and provide comfort and effective pain control in adolescents. More research is needed to examine the determinants of some pain management used by adolescents including how and why they choose the way (Campbell & McGrath, 1999). Non-pharmacological therapy, such as regulating sleep patterns, diet, managing stress, exercise, and avoiding pain triggers can be used in managing pain in adolescents (Al Khalili & Chopra, 2021).

Even though several guidelines based on various studies are available, pain in children and adolescents is still

underestimated and ignored. In addition, assessment and assessment as well as documentation of pain are still lacking, and the drug prescriptions given do not comply with guidelines. Pain levels must be assessed accurately both at rest and when moving to get a more comprehensive picture of pain in children. The response to treatment must be monitored regularly to prevent the pain from getting worse and being difficult to treat. Inter-professional communication and an ethical stance are essential for pain management in children and adolescents receiving hospital care. Non-pharmacological methods also have different benefits for each child with pain apart from pharmacological interventions. This study suggests that it is important to improve pain care beyond specialized tertiary clinics. Future research could focus on finding factors that reduce the gap between guidelines and clinical practice in pain treatment (Andersson et al., 2022).

CONCLUSION

This research concludes that further education of pain self-management and self-awareness about pain management are very necessary for teenagers who experience cancer. Patient education is also very important and is combined with teaching about self-management and coping strategies when teens experience pain. This can increase the experience of effective pain management in adolescents. Therefore, nurses in all areas of care, not just those working in pediatric care facilities, need sound knowledge of adolescent pain management to facilitate effective and efficient nursing care. Continued prospective data collection in children and adolescents with more advanced stages of cancer can be carried out regarding the frequency of symptoms, severity and level of distress due to excessive pain. Increasing physicians' and nurses' understanding of the experience of signs and symptoms can



improve communication with children and adolescents and timely intervention. More research is needed to understand symptoms and pain control in children with more advanced stages of cancer. It is hoped that parents, families and health care providers can be more active in providing education regarding pain management, so that it can indirectly improve the quality of life of children with cancer.

CONFLICT OF INTEREST

We certify that there is no actual or even potential conflict of interest in completion and relation to this article.

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