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Pain Self-Management by Cancer Patients Treated at RSUP Dr. Kariadi Semarang

Arief W. Jadmiko^{1,4,*}, Tri Nur Kristina², Untung Sujianto², Yan W. Prajoko², Luky Dwianto²,
Aris Puji Widodo³

¹ Doctoral Student of Medicine Faculty, Diponegoro University, Semarang, Indonesia

² Faculty of Medicine, Diponegoro University, Semarang, Indonesia

³ Faculty of Science and Mathematics, Diponegoro University, Semarang, Indonesia

⁴ Nursing Department, Faculty of Health, Universitas Pembangunan Nasional Veteran Jakarta, Indonesia

Abstract: This article describes a new overview of in-depth information about cancer patients' experiences with pain management independently. The study uses a qualitative approach to patients with cancer diagnoses who are treated at Dr. Kariadi Semarang. We used the purposive sampling technique to select the respondents. In-depth interviews collected data. Two researchers independently coded transcript data. We used the Atlas.ti software to perform data analysis. Furthermore, the preparation of the report uses the COREQ guidelines. The results of this study obtained four research themes. Four themes emerged that describe the experiences of participants in their efforts to carry out pain management independently, namely diverting the pain they feel by: (1) Doing daily activities, (2) Doing religious activities, (3) Doing social interactions, and (4) Looking for a pleasant environment. Thus, cancer patients try to manage the intensity of the pain scale independently by doing activities that are believed to shift the intensity of the pain scale by daily activities, social activities, spirituality, and interacting with the environment. The participants' experiences in this study reveal each individual's uniqueness in carrying out pain management independently. The results of this study can be used to develop various independent (non-pharmacological) nursing interventions based on the uniqueness of each individual.

Keywords: pain management, cancer, non-pharmacology.

RSUP治疗的癌症患者的疼痛自我管理卡里亚迪·三宝垄博士

摘要: 本文介绍了有关癌症患者独立疼痛治疗经验的深入信息的新概述。该研究使用定性方法对由卡里亚迪·三宝垄医师治疗的癌症诊断患者进行了研究。我们使用目的抽样技术来选择受访者。深入访谈收集了数据。两名研究人员对成绩单数据进行了独立编码。我们使用Atlas.ti软件进行数据分析。此外,报告的编写使用了核心问卷指南。这项研究的结果获得了四个研究主题。出现了四个主题,这些主题描述了参与者独立进行疼痛管理的努力中的经验,即通过以下方式转移他们的痛苦:(1)进行日常活动,(2)进行宗教活动,(3)进行社交互动以及(4)寻找一个愉快的环境。因此,癌症患者试图通过进行被认为通过日常活动,社交活动,灵性和与环境的相互作用来改变疼痛量表的强度的活动来独立地控制疼痛量表的强度。参与者在这项研究中的经验揭示了每个人在独立进行疼痛控制方面的独特性。这项研究的结果可用于根据每个人的独特性开发各种独立的(非药理学)护理干预措施。

关键字: 疼痛管理,癌症,非药理学。

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About the authors: Arief W. Jadmiko, Doctoral Student of Medicine Faculty, Diponegoro University, Semarang, Indonesia; Nursing Department, Faculty of Health, Universitas Pembangunan Nasional Veteran Jakarta, Indonesia; Tri Nur Kristina, Untung Sujianto, Yan W. Prajoko, Luky Dwianto, Faculty of Medicine, Diponegoro University, Semarang, Indonesia; Aris Puji Widodo, Faculty of Science and Mathematics, Diponegoro University, Semarang, Indonesia

Corresponding author Arief W. Jadmiko, ariefwjadmiko@gmail.com

1. Introduction

Pain is a complaint that is often reported and most feared by cancer patients. The prevalence of pain complaints in cancer patients is still high (55-72.9%) [1], [2], and 38-50% of them are included in the moderate and severe pain scale category [2], [3]. The intensity of the pain scale is a complaint that is influenced by each individual's unique characteristics, resulting from a complex interaction between physical, psychological, spiritual, and social factors that affect individuals' physical and mental well-being [4].

Various efforts to manage pain in cancer patients have been carried out using pharmacological and non-pharmacological techniques [5]. However, several studies have stated that 56-82.3% of cancer patients still report constant pain complaints, feel they are not getting optimal pain management. Besides, a third of patients say no received analgesics according to the intensity of their reported pain scale [3], [6], [7].

Not optimally pain management can be caused by the assessment of the intensity of the pain scale that is not suitable, the subjectivity of the assessment of the intensity of the pain scale, and the therapy that is not suitable for the unique characteristics of the individual and the causes of pain that the sufferer feels [8], [9]. Pain that is not treated optimally results in an increased risk of psychological disorders where 15-19% of cancer patients experience major depression, 8-10% anxiety [10], 38% mood disorders [11], [12], [13] and 14-32% wish to end their life [10],[14],[15],[16],[17]. This condition triggers a serious impact on cancer patients' quality of life, as evidenced by the data that 82.3% of cancer patients are in the low quality of life category [1].

Legally and ethically, the nursing profession is responsible for providing comprehensive nursing care (bio-psycho-socio-cultural-spiritual) to cancer patients with complaints of pain and various problems through non-pharmacological therapy [18], [19]. Non-pharmacological techniques in reducing the intensity of the pain scale focus on physical aspects and strengthen the psychological, spiritual, and social domains that aim to provide greater comfort and be independent of patients in overcoming each problem [20].

There are two non-pharmacological pain management, peripheral therapy including hot and cold compresses [21], transcutaneous electrical nerve stimulation (acupuncture, acupressure, massage, hydrotherapy, exercise), and cognitive behavioral therapy, including relaxation techniques, meditation, prayer, yoga, hypnosis, biofeedback [4], [22].

According to the individual's unique characteristics, pain management can prevent unnecessary suffering, improve the quality of life, and prevent the sufferer from feeling helpless and hopeless [23]. Conversely, failure to consider the uniqueness of individual characteristics and various trigger factors (physical, psychological, spiritual, and social) when determining

the cause of pain will result in an inappropriate pain management plan for each individual [24].

The novelty of this research is that the researcher compiles interview guidelines using the Kolcaba convenience theory approach. This comfort theory focuses on the factors related to the optimization of the comfort level in individuals. So it is hoped that the research will be able to provide an overview of the activities carried out by participants in managing the pain they feel to increase their comfort objectively.

Understanding pain management based on the uniqueness of each individual's characteristics is essential to formulate an appropriate pain management plan. With a better and deeper understanding of what individuals expect when experiencing pain, this provides essential information that is important for nurses to formulate a pain management plan appropriate for the pain experienced by cancer patients. Obtaining comprehensive information from the experiences of cancer patients who are successful in carrying out pain management will support more optimal pain management. This study aimed to get in-depth information about the experiences of cancer patients in managing pain independently.

2. Methods

This is qualitative research with a phenomenological approach that focuses on cancer patients' daily experiences in reducing their pain. Selection of participants using purposive sampling method with inclusion criteria including:

1. Age 18-60 years.
2. Having cancer for more than six months.
3. Having pain experience with a scale of > 3.
4. Cancer stage I -III.
5. No communication problems and dementia.

The research was conducted in RSUP Dr. Kariadi Semarang in June - August 2020. Data collection was carried out using the in-depth semistructured interview for participants and stopped until the data were met (saturation) and no new topics emerged. Interviews were conducted by the main researcher (AWJ), who has various training certificates in qualitative research. Interviews were conducted in the participant's ward because of the participants' conditions that made it impossible to move to another room. We were always ensuring that the interview conditions were conducive and maintaining the participants' confidentiality. Interviews were recorded using a Sony brand recording device IC Recorder ICD-PX470 with an interview duration of 30-45 minutes.

The Kolcaba Comfort theory guided the interview. The participants' main questions are as follows:

- (1) What influenced the level of pain you felt?
- (2) What do you do if you have pain?

2.1. Data Analysis

Data analysis was performed using the Miles and Huberman method. The transcript of the interview was done by playing back the record and writing it in words. Field notes (field notes) and observation results are integrated into the transcript according to the incident response when data collection. We use the Atlas.ti software to help extract units, codes, and categories word by word from compiled transcripts. The coding is done independently between AWJ and AB. Furthermore, the preparation of the report uses the COREQ guidelines.

2.2. Trustworthiness

The interview transcripts were returned to the participants to ensure that they were in accordance with what was conveyed during the interview.

2.3. Ethical Review

This research has been reviewed and approved by the Ethics Committee of Dr. Kariadi Semarang (No. 530/ EC/ KEPK-RSDK/ 2020). All participants signed an explanation and informed consent before taking data.

3. Results and Discussion

Eight cancer patients met the inclusion criteria and participated in this study. Participants in this study consisted of patients with Ca Mamae, Ca Cervic, Ca Ovarii, Fibrosarcoma, and Ca Colli, with an average age of 38 years with an age range of 21-53 years, 7 participants were married, and 1 participant was unmarried. Based on the results of the analysis, four themes were obtained that describe the experiences of participants in their efforts to carry out pain management independently; namely, the participants tried to shift the intensity of the pain scale they felt by (1) Doing daily activities, (2) Doing religious activities, (3) Doing social interaction, and (4) Looking for a pleasant environment.

3.1. Reducing Pain by Doing Daily Activities

The majority of participants do the activities they like best to divert their pain and feel happy and calm. Some of the activities carried out to hinder the intensity of the pain scale include cooking, walking, leaving the room, washing dishes, or cleaning the house. Some quotes from participants are as follows:

Whenever I feel pain, I always do activities such as walking, cooking, playing with children, washing dishes, cleaning, or watching TV; sometimes, the pain I feel is less and somewhat comfortable. P1, P3, P6, P7

If I am not active when the pain occurs, the pain usually increases. P1, P3

According to most of the participants doing these activities, they could divert the pain they felt because their minds did not focus on their pain.

... By doing activities that we like, sometimes I can forget the pain I feel because maybe we are busy with our activities. P5, P6, P7

3.2. Reducing Pain by Doing Religious Activities

Apart from doing their preferred daily activities, other efforts made by the participants to reduce the intensity of the pain scale independently include doing religious activities such as praying/dhikr, listening to spiritual songs/recitation. Some of the quotes from the interview results regarding the religious activities carried out by the participants are as follows:

Praying can reduce the pain felt by the participants:

Whenever I feel pain and no one is around, I usually pray, pray and recite the Koran. After praying, my mind became calm, joyful, comfortable, and the pain I felt lessened. That belief can sometimes lead me to believe that these activities can relieve the pain I feel. P2, P4, P6

Apart from praying, the participants also did activities to listen to spiritual songs:

...Listening to calm music. I enjoy listening to spiritual music. By listening to spiritual music, I feel closer to God; my heart is calmer until the pain is reduced, and I don't fall asleep while listening to the spiritual song. P2, P4, P5, P7, P8

... Usually, I listen to recitation. By listening to it, I sometimes feel less pain. P3

3.3. Doing Social Interaction

Our study found several participant activities in reducing pain independently, through social interaction with family and community. The quotations from participants are as follows:

...if the pain is usually relieved by chatting and telling stories with the closest people (husband, wife, father, mother, and child) and neighbors. By chatting sometimes, I forget the pain I feel, and sometimes I get encouragement and motivation from them. However, if there is no one when there is pain, the pain is more pronounced. P1, P3

.... I hope that the nurse can provide advice, input, and motivation to me to be calm. P1, P5, P6

3.4. Looking for a Pleasant Environment

Our study found some participants' activities and expectations to reduce pain independently by finding a comfortable and pleasant environment. According to the participants, the pleasant atmosphere was the natural atmosphere (mountains, beaches, privacy, countryside, trees, rivers, calmness and not crowded, rice fields, places of worship, hills, sunrise) and room atmosphere (quiet/calm, privacy and relaxed). Some quotes from the conversations of participants about activities and expectations about a comfortable natural environment that can reduce pain are as follows:

...which is a quiet, comfortable place, the place is excellent, the people are not busy in the city, maybe in the countryside. Yes, like in the countryside, so comfortable. Lots of trees, the air is fresh and unspoiled. Seeing green rice fields, which makes it comfortable and makes it calm. P6

Usually every morning I like to go to my mother's house. There I could see the sunrise, the view of the rice fields; there is rice that is still green or yellow, in the middle, there is a mosque, there are hills, lots of trees, and there is a river that divides the rice fields, so the pain I felt was as if I didn't feel it. P1

... in the mountains there are green hills, beautiful and rare scenery, cool and makes us not bored so that it makes us comfortable. P3, P6

... mountain views, I can feel the coolness and can see lots of green trees. It makes us comfortable, and we are not focused on the pain you feel; you can refresh it. P8

A quiet environment like a beach view. P5

Participants feel that they can control the pain by resting in a room with several conditions, including a quiet, private room. Some of the quotes from participants are as follows:

... The environment is quiet, lonely, cool, and there is no noise. P2, P3

Yes, sometimes, if it hurts a lot, I ask my child for help to condition the environment around me so that it is calm and away from the noise. Because I'm sure the pain gets less when it's calm. P4

Usually, when I feel sick, I feel comfortable in the room—quieter and more privacy than other rooms. Usually, in the room, I think about positive things to overcome the pain I feel while watching TV and listening to music. If it is outside, it might not be quiet because there are siblings or other people; if you are in the room, you can rest and be calmer. P5

The condition of my house is very crowded. When I am at home, I cannot calm down, and it gets more painful at home because, in one house, many brothers live together. Usually, a lot of children make noise and crowded. Such busy conditions sometimes add to the pain I feel until I cry and permanently close the bedroom door. P6

4. Discussion

This study aimed to find out in-depth how the experiences of cancer patients in pain management independently. The results showed that most respondents made efforts to divert and reduce their pain by doing daily activities, doing religious activities, doing social interactions, and finding a comfortable environment.

These various efforts are part of the diversion or distraction method that is carried out to not focus on the pain that is being felt. One of the most commonly used non-pharmacological interventions is distraction. Koller and Goldman define distraction as a cognitive

and behavioral strategy that draws attention away from painful stimuli [25]. Distraction is a highly recommended non-pharmacological intervention for pain management and is often indicated as a nursing course. Distraction modifies the cognitive perception of pain by altering the nociceptive response and triggering the system for internal pain [26], leading to decreased activation of areas in the brain (thalamus & insula) that contribute significantly to pain perception [27].

The following is an explanation of each theme obtained:

4.1. Performing Daily Activities

In their efforts to reduce pain independently, most participants, carrying out daily activities, including walking, cooking, washing dishes, and doing housework. According to them, doing this activity makes them feel happy and can divert their attention from their pain. Spatially directed attention to carrying out activities can reduce individual concentration and attention to other existing stimuli. These results suggest that directed attention modulation of sensory suppression may provide a key selection mechanism in the human extrastriate cortex. When the individual directs attention to a specific object in the visual scene, the visual cortex's response to stimuli presented at that location is enhanced. The suppressive effect of another distractor (pain sensation) is reduced [27].

4.2. Doing Religious Activities

Other efforts made by the participants to reduce the intensity of the pain scale independently include doing religious activities, namely praying/dhikr, listening to spiritual songs/recitation. The spiritual level is a predictor of pain acceptance, so more religious patients tend to be more tolerant of chronic pain [28]. One of the factors that influence patient pain is considering the level of spirituality and religion [29], [30]. Individuals who participate in religious activities or have strong religious beliefs also have high mental health. The relationship between religion and health is essential in many ways [31], and the need for spirituality is considered one of the factors that relate effectively to health [32]. Individuals who have faith in God are more likely to have a level of resistance to the various problems they face [33]. *Understanding the meaning and concept of life and* belonging to God can increase the spiritual level in the dimension of human existence, leading to the ability to adapt to disease [34], [35].

Spiritual well-being is defined as a sense of communicating with others, having meaning and purpose in life, having faith in transcendental powers, and communicating with God, which is effective for individuals' physical and mental health [36], [37]. Research conducted by Jesemi et al. [38] on patients with burns in Iran showed that there is a significant relationship between the level of spirituality and the severity of pain experienced by patients. A qualitative

study conducted by Moeini et al. on cardiac patients in Iran shows that patients perceive pain as a form of God's destiny. Patients believe that religious acts such as praying and giving thanks to God are important factors in pain relief [39].

4.3. Doing Social Interactions

Our study found several participant activities in reducing pain independently, namely through social interaction with family and community. Evidence suggests that not only cognitive and emotional factors [27], [40], [41], [42], but also social factors can modulate the experience of perceived pain [43], [44]. Chronic pain patients with a high level of social support experienced less stress and less severe pain, and when the level of support is higher, the individual is better able to adapt [38], [45], [46]. Social support can contribute to chronic pain management because it includes psychological, social, and environmental factors [47].

The social environment affects how the intensity of the pain scale is felt and expressed. The pain scale intensity was assessed to be less felt when the individual was with a partner than when they were alone [48], [49], [50], [51], [52], [53], [54]. Other studies have also provided evidence that social context affects pain scale intensity [55], [56]. Lack of social support has been associated with higher pain intensity in fibromyalgia patients [57] and in the elderly [58], [59], [60]. Breast cancer patients who did not receive social support reported a higher intensity of pain scale than patients who received social support [61].

Social support has proven to be very important in assisting individuals in managing life crises and health challenges [62]. Effective social support for breast cancer patients has also been shown to help reduce the negative impact of diagnosis, treatment and improve their psychological well-being [63], [64]. Social support can be provided by close friends, family, health professionals, and the community in the form of support that is instrumental, structural and functional, emotional, and informational [65].

There is a link between support systems and coping strategies among women diagnosed with breast cancer. Individuals with more social support sources are more likely to adopt coping strategies than those with fewer sources of social support [66]. Social support improves individual survival by enhancing coping skills with emotional support and broadening information sharing opportunities [67].

4.4. Looking for a Comfortable Environment

Our study found several activities and expectations of participants in supporting their efforts to reduce pain independently by finding a comfortable and pleasant environment. Ulrich & Giplin [68] explained how image representation with themes related to stretches of water, natural landscapes, flowers, gardens, and

figurative art displayed emotionally according to gestures and positive facial expressions can reduce stress and reduce the intensity of the pain scale. Visual stimulation can also serve as a distraction to make painful therapeutic procedures more bearable [69].

Studies show that individuals treated in a room with views of nature (trees) have a shorter postoperative stay and require minimal analgesics than those treated with a view facing a wall [70]. Individuals treated at the hospital view the plants and the environment outside the room in favor during hospitalization [71]. Beauchemin & Hays found that patients had a shorter length of stay if they lived in a bright room compared to a dim room. Patients treated in bright rooms had a mean stay period of 16.6 days, while those in dim rooms had 19.5 days [72], [73]. Deaths for both sexes were also consistently higher in dim room conditions. Choi et al. [74] noted that high illumination in the morning is more beneficial than light in the afternoon.

5. Conclusion and Recommendations

Complaints of pain in cancer patients that impact life quality require a deep understanding for nurses in providing nursing care. Understanding the patient's experience in carrying out pain management is an effort made by nurses to provide appropriate interventions from each individual's unique characteristics. Cancer patients conducting religious activities, carrying social interactions, and finding a comfortable environment, which they believed can divert and reduce the pain scale's intensity. The experiences shared among the participants in this study confirm each individual's uniqueness in carrying out pain management independently and the need for interventions designed to improve the individual's ability to manage non-pharmacological pain management.

5.1. Contribution to Nursing Practice

The study results can contribute to nursing practice through information about the initial description of the uniqueness of each individual in responding/managing pain independently of the pain they feel. This understanding of the uniqueness of each individual's response to pain can be used to determine which non-pharmacological pain management interventions will be given to the individual appropriately. In addition, the results of this study can also be used to modify and even create new pain management interventions based on the uniqueness of each individual in responding to perceived pain.

5.2. Limitation

This study's limitation is that the sample in this study is patients treated in a tertiary type hospital (top referral), wherein its management, of course, also receives pharmacological therapy. Other things that may affect the patient's success in dealing with pain

independently are, of course, influenced by the drugs given and the physical condition of the patient himself. Besides, the sample's distribution in this study was dominated by women, so further research must add a sample with the male gender. However, understanding the patient's managing pain is beneficial for increasing non-pharmacological pain management options.

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