

Research Article

A Qualitative Study of the Experiences of Children With Cancer and How They Perceive Their Problems During Hospitalization in Indonesia

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Abstract. Children with cancer will find it challenging to participate in social activities, especially outdoor ones. This can lead to poor interpersonal skills, loneliness, and low self-esteem. Children who are diagnosed with cancer, particularly a terminal form, have a variety of requirements, including the need to communicate and discuss, as well as the need for social support to aid in coping. Thus, the purpose of this study was to explore the experiences of children with cancer and how they perceive their problems during hospitalization in Indonesia. The research used qualitative exploratory techniques with patients receiving treatment in the Dr. Sardjito Hospital's Children's Health Installation in Yogyakarta. Purposive sampling was used for recruitment. The picture codes approach with photovoice was applied for data collection. The data were evaluated conceptually, and emerging themes were substantiated by statements from participant interviews. Three themes emerged: painful medical procedures that traumatize youngsters, indoor facilities that provide comfort for children, and playmates similar to siblings. Developing the necessary support programs for these children involves meticulous planning and preparation, which must begin even before children return to school and involve teachers, health care providers, and family members.

Keywords: cancer, children, problems, hospitalization, qualitative study

1. Introduction

Cancer affects between 2% and 4% of children and causes for 10% of pediatric fatalities [1]. About 600 children under the age of 16 are diagnosed with cancer; 6.7 million people died from cancer, and 24.6 million people live with cancer [1]. Cancer can also affect a child's development and social function. Children with cancer will find it challenging to participate in social activities, especially outdoor ones. This can lead to poor interpersonal skills, loneliness, and low self-esteem [2]. Also, side effects of cancer treatment include hair loss and weight gain (from steroids) can cause low self-esteem [3]. Over one-third (35%) of parents of children with cancer indicate that their child has been bullied or ridiculed by peers as a result of their cancer diagnosis or treatment [2].

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The present management of cancer in children must be done in a professional and ethical manner. According to the National Institutes of Health (2019), chemotherapy, biological treatment, radiation therapy, cryotherapy, bone marrow transplantation, and peripheral blood stem cell transplantation are all used to treat cancer in children. Chemotherapy, radiation, and surgery together have been found to prolong life in cancer children. They are administered for an extended period of time and frequently cause discomfort to the youngster as well as adverse reactions. Chemotherapy can have physical, social, emotional, and cognitive impacts on children, according to [4]. Symptoms of this medication's adverse effects include conditions such as: a weak immune system, exhaustion, anemia, hair loss, difficulty healing, and diarrhea. sleep. In addition to medical concerns, another adverse effect is that children have psychological problems, such as mood problems, anxiety, loss of self-confidence, a decline in perspective of themselves, depression, and behavioral change [5].

All of these factors impact children's general well-being [2]. Numerous studies indicate that children diagnosed with cancer have a low quality of life [6]. However, the perceptions of children with cancer regarding their quality of life are frequently overlooked and are not factored into the development of a child's treatment plan [6]. Understanding how treatment-related side effects affect quality of life is critical in determining if patient management has to alter.

Children who are diagnosed with cancer, a terminal condition, have a variety of requirements, including the need to communicate and discuss, as well as the need for social support to aid in coping [4]. As a result, the presence of parents and family members is critical for children who are terminally ill [7]. [8] noticed that children hospitalized face a variety of challenges, including isolation from family and friends, unpleasant treatment, strange surroundings, and missed opportunity for play. This implies that children can be distressed while in the hospital and need nurses to help them relax. Children with cancer face numerous challenges; it also has an effect on the complex demands of families with cancer-stricken children. Numerous needs have been identified as those of family members of children with cancer. These include the need for physical comfort, emotional support, cultural awareness, familial support and aid, and a greater capacity for self-management [9]. Children must receive prompt and proper treatment in order to adjust to their new circumstances. Health care workers would be far better if they had an in-depth understanding of what their child's cancer treatment will entail, and would be more competent in their professional role. Thus, the purpose of this study was to explore experiences of children with cancer as they perceive about their problems during hospitalization in Indonesia.

2. Methods

2.1. Study design

The research used a qualitative exploratory technique [9]. The participants for the study lived in Yogyakarta, Indonesia, during the time of the COVID-19 pandemic.

2.2. Sample

Patients receiving treatment in the Dr. Sardjito Hospital's Children's Health Installation in Yogyakarta. A total of six children took part in this research study. Children who are rich in information are chosen based on a number of criteria, including having received treatment at least once at the Dr. Sardjito Hospital Yogyakarta's Children's Health Installation, being between the ages of 7 and 12 years old, being cooperative, being in good physical condition, being willing to participate, and being able to use a camera device to take photos of themselves. Choosing the number of samples in qualitative research is determined by the concept of data saturation, which states that sampling will be stopped if there are too many similarities between the data from the interviews. According to [10], the number of samples in qualitative research should range from a minimum of 6 to a maximum of 10 people. Purposive sampling was used as the sample technique.

2.3. Procedure

The picture codes approach with photovoices was applied to explore data on children cancer. One of the data gathering methods used in this study is photovoices conducted by the research subjects, who are children. The data generated are photographs taken by children of nurses performing behaviors that are either liked or disliked by youngsters. It is possible to photograph the nurse's face in the photograph. Of course, if the child does not approve of the activities made, the nurse will experience psychological distress. To safeguard it, the researcher will conceal the photo on the body, namely the face and mouth, in order to preserve the nurse's identity. In the opposite direction, photographs taken by youngsters can cause psychological distress to children and families. There are concerns that the nurse would treat the child differently if it is discovered that the photographs, they take care of things they dislike. To avoid causing hardship to informants (children and families), researchers will conceal

informants' identities and will not publish photographs. Photographs will be retained by researchers as research archives.

2.4. Data analysis

The data were evaluated conceptually, and emerging themes were substantiated by statements from participant interviews [10]. To facilitate analysis, NVivo was used to organize the data.

2.5. Trustworthiness

The data's validity is determined by the researcher's ability to demonstrate its dependability, validity, and objectivity. The validity of data is determined by four criteria: trustworthiness (credibility), transferability (transferability), dependability (dependability), and certainty (confirmability). To improve trust, member checking is also conducted, in which the researcher confirms the results of in-depth interviews and focus groups with research subjects or data sources. This is done to guarantee that the results of the in-depth interviews and focus groups are accurate. The transferability criterion considers if the research findings may be applied to another location, time period, or issue based on the audience. The technique used in this study is to create a detailed (thick) explanation of the research findings. The research will be detailed in full, clearly, logically, and sensibly, so that the outcomes from each stage of the investigation will be more realistic. On the basis of the reliance criterion, the technique used to strengthen the validity of the data in this study is triangulation, either of data sources or of data sources derived from children with cancer using the picture codes method with photovoice.

3. Results

The six patients in this study were three boys and three girls, ranging in age from eight to fourteen years, and had completed elementary or junior high school.

The photovoice method was used to collect data on the patient's perspective on therapy. According to the analysis's findings, the perspective of children with cancer elicited more favorable responses. Three themes emerge: painful medical procedures that traumatize youngsters, indoor facilities that provide comfort for children, and playmates similar to siblings. The first themes that arose from the informants' expressions were

painful medical procedures that damaged children. For children, medical intervention remains a bad experience and response, as indicated by one of the informants:

"That's a photo; I don't like it when I put an IV in it." (P2)

"I dislike having infusions maintained; they're replaced and shifted every three days.... (P1) Positive responses from children with cancer are stated in terms of indoor facilities that make them feel at ease and playing brothers.

"Acquiring a large number of toys is equivalent to lying in bed and playing games." (P1)

"I have a lot of pals, including my brother; our house is quite a distance away, but we have a good time playing together, despite the fact that we are both ill and on an IV." (P2)

The informant stated that he was fearful of facing repeated activities on a daily basis for an extended length of time, and then he experienced the consequences of these actions.

"Ra dislikes injections because they hurt.... continues to get injected daily" (P1)

"If I dislike having an IV, I have to change it every three days, and when I move, my hands frequently swell." (P3)

In addition to issues of action, the informant expresses unpleasant feelings about the moment of parting from the peer group. Patients who are still in their childhood and enjoy playing with their friends feel as though they are missing out on the opportunity to play with their pals while undergoing therapy.

"I dislike it when the medicine is not available, therefore I avoid returning home." (P5)

Things that elicit enthusiasm and enhance patient satisfaction, as indicated by informants about the facilities given, make them comfortable.

"The playroom is stocked with a variety of toys...which can be brought into the room as well." (P5) *"Acquiring a large number of toys is equivalent to lying in bed and playing games." (P1)*

4. Discussion

Children during treatment have a need for friends, both those with cancer and classmates who are not affected by disease. Peers perform a critical psychological function, according to research. Friendships with similar cancers are frequently viewed as people who 'really understand' what it means to have cancer, which makes it simpler to express

someone's emotions openly and honestly. Non-cancerous companions are priceless because they assist children in reestablishing a sense of normalcy and connection with their non-cancerous self [8]. However, because cancer is a chronic disease with several physical side effects, associating with friends, particularly non-cancerous friends, and participating in some leisure activities (particularly physical activity) can be challenging. As a result, it is necessary to provide support for children with cancer, opportunities for them to interact with peers (both cancer and non-cancer), and opportunities to participate in a variety of recreational activities. Weekend/holiday activities for children with cancer and cancer support groups for children are generally seen positively since they provide opportunities for children to gather and discuss issues and offer support to one another in a relaxed setting.

Many children with cancer spend extended amounts of time away from school and rarely see their friends throughout their illness; consequently, returning to school is critical for reestablishing normal routines and continuing social, emotional, and intellectual development. Additionally, it gives a good and useful outlet for children's attention away from social and academic pursuits [6]. Returning to school, on the other hand, is frequently perceived as troublesome, particularly for children and adolescents who are deemed more vulnerable or who demonstrate social and emotional adjustment and behavioral difficulties, such as depression, social disengagement, and lack of self-confidence [10]. There is something intriguing about how frequently parents, teachers, and non-cancer peers regard children with cancer as a problem rather than as children with illness.

Children with cancer have been demonstrated to perceive themselves as socially competent and hence become disappointed when their treatment is altered [5]. Returning to school certainly presents a slew of practical and emotional challenges for children, ranging from completing assigned work to reestablishing social contact with peers to responding to other people's inquiries about their cancer [4]. Given this intricacy, a well-planned and organized reintegration program involving hospitals, schools, and family members is certainly necessary.

Effective communication is critical in the treatment of pediatric cancer. Clear and compassionate communication of diagnostic and prognostic information has a beneficial effect on patients' and families' ability to cope. When other therapies have failed, an open and sympathetic talk about treatment goals and expectations for patients nearing the end of life might give healing. Effective communication and the development of positive connections can also be a source of consolation for families grieving the death of a child. There is compelling evidence that excellent communication improves

patients, families, and healthcare practitioners. Critical communication skills that health-care providers can use throughout the course of illness to provide information, promote shared decision-making, foster therapeutic alliances, and empathize with end-of-life issues, so that healthcare providers understand the value of effective communication and master critical skills [3]. The inability of health care personnel to communicate effectively is a significant impediment to providing high-quality care. Numerous studies have revealed unhappiness with the way health care personnel communicate with patients and their families in hospitals.

5. Conclusion

In conclusion, three themes emerged from the patient perspective, notably painful medical procedures that traumatized children, indoor facilities that made children feel secure, and playmates similar to siblings. Developing such a program, in fact, involves meticulous planning and preparation, which must begin even before children return to school and involve teachers, health care providers, and family members. Teachers and classmates in schools should also be prepared and informed about childhood cancer and its prospective effects on children's academic performance.

References

- [1] National Institutes of Health. National Cancer Institute (NCI); 2019.
- [2] Arslan FT, Basbakkal Z, Kantar M. Quality of life and chemotherapy-related symptoms of Turkish cancer children undergoing chemotherapy. *Asian Pacific Journal of Cancer Prevention: APJCP*. 2013;14(3):1761–1768. <https://doi.org/10.7314/apjcp.2013.14.3.1761>
- [3] Hockenberry MJ, Wilson D. *Wong's clinical manual of pediatric nursing*. 8th ed. Elsevier Ltd; 2008.
- [4] Dorothee A. *Spiritual care and palliative care: Opportunities and challenges for pastoral care*. 1998.
- [5] Catlin A, Ford M, Maloney C. Determining family needs on an oncology hospital unit using interview, art, and survey. *Clinical Nursing Research*. 2015;25(2):209–231. <https://doi.org/10.1177/1054773815578806>
- [6] Ji Y, Lacey N. *Experimental transplantation and immunotherapy branch*. National Institutes of Health; 2011.
- [7] Doyle D, Hanks G, Cherny NI, Calman SK. *Oxford textbook of palliative medicine*. 3rd ed. Oxford Medical Publications; 2013.

- [8] Coyne I, Murphy M, Costello T, O'Neill C, Donnellan C. A survey of nurses' practices and perceptions of family-centered care in Ireland. *Journal of Family Nursing*. 2013;19(4):469–488. <https://doi.org/10.1177/1074840713508224>
- [9] Binder, K., Ceperley, D. M., Hansen, J. P., Kalos, M. H., Landau, D. P., Levesque, D., ... & Weis, J. J. 2012. *Monte Carlo methods in statistical physics (Vol. 7)*. Springer Science & Business Media. 2012
- [10] Blazin LJ, Cecchini C, Habashy C, Kaye EC, Baker JN. Communicating effectively in pediatric cancer care: Translating evidence into practice. *Children*. 3018;5(3):40. <https://doi.org/10.3390/children5030040>