

ORIGINAL ARTICLE

Complex Care Demands of Children With Cancers: A Qualitative Study

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ABSTRACT

Introduction: Family caregivers deal with complex problems such as diseases progression, treatment conditions, social and financial burden of children with cancer. The purpose of the study is to investigate the care needs of children with cancer from the perspective of family caregivers in Yogyakarta, Indonesia.

Methods: This study used content analysis. The researchers collected the data with interviews with 8 parents. **Results:** First theme was patients-based needs which are consisting of physical and psychological needs, and family involvement. Second theme was family-based needs that related to economic problems, information needs and spiritual support. **Conclusion:** Parents who care for children with chronic illness have a range of needs, including open and honest communication with health care providers, in-home care, and long-term care. Parents desire not only sensitive information supplied by well-trained experts, but also recognition of the crucial nature of bridging support, i.e., benefits not lost immediately following a child's death.

Keywords: Needs, Care, Cancer, Children, Survivor, Caregiver, Qualitative study

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INTRODUCTION

Cancer is one of the most devastating diseases in the world, claiming the lives of over 500,000 people each year. The WHO predicts a seven-fold increase in cancer patients in Indonesia by 2030. The number of cancer patients who have died is likewise on the rise (Ministry of Health, 2015). In Indonesia, 2–4% of all cancer cases are children. According to data discovered, around 4000 new pediatric cancer patients are diagnosed each year which the reason is unknown (1). It is responsible for ten percent of all child fatalities. The majority of cancer deaths occur in children aged 5-14 years.

Chemotherapy, radiation, and surgery together have been found to prolong life in cancer children. These actions are repeated for a long period, causing discomfort and negative effects in the child. Infections, easy bleeding, tiredness (fatigue), lethargy, hair loss, mucositis, nausea, vomiting, diarrhea, constipation, decreased appetite, neuropathy, hemorrhagic cystitis, moon face, and other illnesses are some of the physical adverse effects. sleep. Aside from medical issues, children suffer from psychosocial issues such as mood disorders, anxiety, lack of confidence, diminished self-perception, depression, and behavioral changes that prevent them from attending school (2).

Many difficulties and needs of cancer patients necessitate professional care. These issues and needs manifest themselves in adults through daily tasks (self-care, bathing, dressing, and toileting), as well as physical symptoms (pain, fatigue, sleep problems,

shortness of breath, coughing, itching, numbness, night sweats). daily, psychological (depression, fear, inability to cope, inability to express feelings), autonomy (becoming dependent on others, loss of control over life). Difficulty accepting the sickness, understanding the meaning of death) and social (difficulty communicating about illness due of worry) (3). Some of these issues and needs affect children. The child's parents are partners in determining child nursing care family-centered care (Institute for family-based care, 2011). Given the aforementioned, this study aimed to investigate the care needs of children with cancer from the perspective of family caregivers.

MATERIALS AND METHODS

Sample

The participants in this study were parents of survival cancer children and had been treated at the pediatric oncology room at Dr Sardjito Hospital in Yogyakarta at the time of the research. There were intended to be ten participants, however two people withdrew prior to the interview. Families of children who had been treated were asked to share information about other family survivors who fulfilled the requirements for parents of children now recuperating and willing to participate.

Study design

A content analysis technique was used to analyze the care demands of children with cancers, based on the perspectives of caregivers in Yogyakarta, Indonesia. The use of content analysis is beneficial while performing qualitative research (4). Qualitative interviews were the most appropriate method for this investigation because they allow respondents to explain the subjects raised by the questions (5). Approval of ethics was obtained from the Sekolah Tinggi Ilmu Kesehatan Ngudia Husada Madura .

Procedure

Face-to-face, semi-structured interviews lasting an average of 30 to 45 minutes were used to collect data for this investigation. Interviews were conducted at clinic during their clinical visit. A tape recorder was used to record the in-depth interview stage, which was conducted entirely by the researcher himself. The data/answers that are provided by the respondent are double-checked, with any answers that the respondent gives being repeated back to the respondent to confirm the respondent's intentions. The research assistant then transcribed the transcripts of the interviews that had taken place.

Data analysis

Individual interviews with primary nurses were transcribed verbatim from audiotaped recordings. Content analysis was used to examine the data, which

consists of five primary sections: familiarization, coding, theme formulation, thematic description, and reporting (4,6,7). Initial interviews were conducted and then the data were examined. The findings of the survey were reviewed, and a list of questions was compiled for use in focus groups and interviews in order to justify or approve respondents' responses. Many readings were done to get a more comprehensive knowledge of the findings. It was necessary to describe the important issues, principles, and themes during the second stage. Data was analyzed line by line in order to demonstrate the code merges. To construct the substance of the attestation, the abstracting units of meaning were labeled with symbols after they had been condensed into smaller units. In the third stage, several codes were compared and classified into corresponding subcategories and categories based on their differences and similarities. The major themes for this study arose from patient interviews and focus group discussions. Two participants conducted an examination of the emergent topics. NVivo 11, a qualitative data analysis application, was used to evaluate all data.

Ethical Clearance

This study was approved by Research Ethics Committee, Sekolah Tinggi Ilmu Kesehatan Ngudia Husada Madura No. 727/KEPK/STIKES-NHM/EC/XII/2020.

RESULTS

Respondents's Characteristics

The interview session included eight study participants. Seven participants were female, aged between 31-46 years, high school education, diploma and bachelor's degree. Table I shows information on participants' demographic data.

Researchers conducted interview on parents of cancer survivors with a total of eight informants. The results of the analysis resulted in several categories and two themes. The resulting categories and themes are closely related to needs.

Theme 1: Patient-based Needs

Parents of survivors believe that multiple comprehensive problems are common in child care. This includes physical problems, psychological problems, and family involvement. When undergoing treatment, the installation of equipment for treatment and the length of time staying at the treatment place makes the patient or child feel problems, both physical and psychological. Side effects of device installation such as infection and emotional changes that are irritable are a common problem.

"...if there are countless infections, it's always all kinds

of infections because all of them have UTIs, there are amoebae, there are bacteria, all kinds of antibiotics, all of them come in, up to the highest.” (P4) (h-3)

“...children get emotional easily, like that, it’s like children’s clothes over there.” (P5) (h-5)

In addition to physical and psychological problems, the age of the child or patient who is not yet an adult, provides a reality that they cannot be separated from their parents or family. Informants revealed that, children still cannot face treatment alone, the fulfillment of their needs still depends on their parents. Although health workers provide good care, children tend to feel safer and more comfortable if their parents or family accompany them.

“Family involvement is it should be very involved; she is my child who can’t live alone...” (P1) (h-6)

“...if it is a small child, it is certain that parents must be involved, it is impossible for health workers to fully handle children under five...” (P4) (h-8)

“...he wants to eat, wants to drink and what we ourselves are... who prepares and gives milk...” (P1) (h-7)

Theme 2: Family-based Needs

In addition to the needs that focus on children or patients, the need for parents as caregivers is also an issue that is considered important by the informants. Family needs were related to economic problems, information needs and spiritual support. The economic problem is the first issue raised by the family. The need to stay in a place of care for a long period of time, transportation costs for other visiting family members, dropping out of work because they have to accompany patients or children are things that were conveyed by the informants.

“...my husband because he also works privately at home, so he also has to not come to work...” (P3) (h-2)

“...the job will be abandoned if the economy is clearly disrupted...” (P4) (h-3)

“...the problem is even more serious when it comes to the economy...” (P5) (h-5)

The informant said that what is most needed besides physical, psychological and economic support, spiritual support is something that also plays an important role in the patient assistance process. The informant said that spiritual intake is very necessary to face the difficult reality. They should get spiritual support from the very beginning of being diagnosed.

“...actually, spiritual needs are very necessary for

parental assistance, because at the beginning, we start being diagnosed until the treatment process...” (P6) (h-12)

“If it’s for needs, I feel a spiritual need, yes.” (P2) (h-7)

“...yes, if your needs are more spiritual, ma’am, you really need spiritual support to be strong in facing this reality, ma’am” (P1) (h-7)

Another thing that is important to families is the need for information. Informants revealed that during treatment they need to get detailed information about the disease and the process of patient care. It is felt that the implementation is still lacking in the process of palliative care and family-center care.

“... looking for recommendations from friends, about anything that is usually fast can increase its HB too...” (P3) (h-3)

“...so that’s why I often consult doctors in other countries, why is it like this, why here in Indonesia, why not?” (P4) (h-9)

“... how many weeks or how long did the treatment continue, yes, my child said...” (P5) (h-4).

DISCUSSION

Parents who care for children with chronic illness have a range of needs, including open and honest communication with health care providers, in-home care, and long-term care. These needs were not satisfied, according to parents of children with chronic disease (chronic illness other than cancer). Involvement in decision-making processes is related to practical assistance for care from the outset of sickness, the availability of professional psychosocial support, and participation in decision-making processes. Empirical studies addressing the requirements of parents of children with life-limiting illnesses other than cancer have documented difficulties connected with being left alone with fears, locating information about the child’s sickness, obtaining financial assistance, and managing day-to-day care (8,9). To overcome any of these obstacles, parents express a need for assistance from the outset of illness and throughout the process of adjusting to new and demanding settings.

Children with life-threatening diseases other than cancer require professional psychosocial support from the time they are diagnosed and throughout their illness, until they are discharged from the acute crisis. As a result, psychosocial support is a critical component of general treatment and will contribute

to future advancements in palliative care for children with life-limiting illnesses. Coordination of health care specialists representing many disciplines continues to be a challenge. Another conclusion revealed that some parents did not require time-out care in community care facilities for children. However, organizations such as hospitals can serve as a resource for parents of children with cancer to learn about specialized care for their kid and to avoid social isolation, particularly during the diagnosis process. The hospital is also a vital location when a family member's health is depressing. Thus, palliative care services based on family-centered care must be strengthened in Indonesia to assist families with palliative care needs.

Parents must endure emotional and mental strain while also carrying out their medical tasks, exercising parental supervision, and fulfilling all other parental roles and responsibilities. (10–12). Parents of children with cancer often experience more physical and psychological distress and see the doctor more frequently than parents of children receiving family-centered treatment. (13,14). According to researchers, the majority of parents bear the stress of parenting, which is associated with caring for their children who have chronic diseases Santo et al., 2011;(15). Caregiver load is characterized as a goal when it is proportionate to the bodily and/or mental impacts of caring for; and as subjective when it is related with negative sensations elicited by caregiver care (16). Understanding disease-related changes in affected family members can assist them in feeling more secure about the future. Additionally, it assists them in resolving family conflicts.(17,18). It's challenging to live with a child who has cancer, much more so when we lack knowledge about the disease and expert help (19,20).

Parents of children with cancer express a need for coordination in terms of their child's care. Numerous studies have demonstrated that a significant number of health care experts present difficulties for parents when it comes to obtaining explanation and organizing various therapeutic managements. As a result, a "key worker/social worker" has been recommended to aid families in organizing resources and care (The Association for Children's Palliative Care, 2009). It has been demonstrated that by recognizing parental duties and contributions to child care, health care practitioners may help maintain the integrity of the parent-child relationship and support parents in overcoming loss of control during hospitalization (21). Previous research has demonstrated that parents endure a range of emotional states and encounter a range of events when their kid is diagnosed with cancer. Another critical aspect is to prepare and assist parents throughout the disease's progress. Prior study has demonstrated the value of professionals

addressing impending events and remedies in advance of their occurrence. Thus, counseling is necessary to provide parents with the time and space necessary to share their emotions in a non-judgmental environment. Recognizing the numerous changes that parents confront in their personal and family lives, it is necessary to consider providing practical help, such as aid with home activities and childcare. Throughout the illness's duration, families face significant financial upheavals as well as practical and emotional difficulties (22).

Having a sick child result in a shift in family income, which frequently results in additional expenses (such as travel to seek treatment, telephone calls, catering for special meals, and transportation). Many parents, particularly moms, change their work schedules during times of illness. paying work or quitting to care for their sick child. Financial changes can have a variety of consequences for families, ranging from immediate income loss to career ramifications for women trying to return to work in the future. Given these numerous changes and concerns, it's unsurprising that parents seek proper information/ advice regarding available benefits and the financial consequences of potential activities, such as quitting employment. Recently, this has been documented in the field of loss (22).

CONCLUSION

It develops issues that are connected to the requirements of children and families in the modern period, based on the experiences of cancer survivors' parents. Parents desire not only sensitive information supplied by well-trained experts, but also recognition of the crucial nature of bridging support, i.e., benefits not lost immediately following a child's death.

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