

## Conference Paper

# The Life Experience of Family As Caregiver in Child with Cancer

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## Abstract

**Background:** Cancer in children is a very complex issue when treatment and care involve families especially parents, peers and other environmental components are needed to help the healing process. **Purpose:** This study aimed to know the experience of family while caring the children with cancer. **Method:** This study was a qualitative study with descriptive phenomenology design. The participants in this study were five people using Colaizzi's analysis technique. **Results:** The results of this study showed four themes, which were the physiological needs and the need for comfort and safety, loss process experienced by the caregiver, overcoming obstacles, and family's decision making. **Conclusion:** Physiological needs that came out from this study were bathing, eating, hyperthermia management, and giving the drug, while the need for comfort and safety described as bringing a child to a health care facility. The loss process starts with denial from family into acceptance phase. The family has strong confidence to overcome the obstacles with believing that the child will be cured. Environmental support with good health care facility and decision-making by the mother also showed in this study. **Suggestions:** The family who also being a caregiver for their children expected to increase their knowledge about cancer and health care provider are required to be capable enough to delivered health education about cancer.

**Keywords:** Cancer, Caregiver, Children, Experience

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Received: 22 September 2019

Accepted: 4 October 2019

Published: 10 October 2019

Publishing services provided by  
Knowledge E

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the responsibility of the ICHT  
2019 Conference Committee.

## 1. Introduction

Caring experience of family with cancer children can affect the parents, especially mothers, not only physically and mentally, but also the social welfare of the parents will be changed too. Fluctuating exchange emotionally on family arises since the early stage until the end-stage of cancer. Parents as a caregiver also experienced sleep disturbance, fatigue, lack of appetite, weight loss orgaindrastically, depression, guilt, anxiety, anger, socialisolation, and any other

health problems [1] Parents who have been interviewed said that taking care of cancer children arouse many health problems. A number of parents explain that sleep disturbance occurs because of the parents feeling anxiety about their children who have suffered from cancer. Parents who look after cancer children at the hospital also explain

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the difficulties to have a good sleep not only in a number of hours but qualitatively. It is aggravated with the condition of the parents who need to wake up at midnight to take care of their children such as feeding, toileting, and making children feel comfortable in their hospitality period.

The chronic disease like cancer in children is a very complex condition where treatment process must involved family, especially parents, peers, and the environment to help the children's healing process. During that time, children must undergo the treatment to prevent exacerbation of cancer cells. Cancer treatments for children are chemotherapy, bone marrow transplantation, radiotherapy, and surgery. It depends on the type and stage of cancer itself. The prognostic of the disease will greater if the children have passed their life span after treatment for at least 5 years [2].

Based on Basic Health Research (2013) the incidences of cancer at young age population are less than 1 year (0.3%), ages 1-4 years (0.1%), ages 4-5 years (0.1%), and age 5-24 years (0.6%). The prevalence based on the sex of male (0.6%) and female (2.2%). The most common types of cancer in children and adolescents are leukemia, brain tumors, central nervous system tumors, lymphomas, rhabdomyosarcoma, neuroblastoma, Wilms tumor, osteosarcoma, and gonad germ cell tumors.

## 2. Methods

This study was qualitative research with a descriptive phenomenological design. Analysis process used Collaizi's analysis technique. This study was conducted at the Rumah Harapan Indonesia- Bandung.

### 2.1. Participants

This study involved 5 caregivers from different family which is meet the inclusion criteria such as family member who acted as a caregiver in cancer children, willing to participate in this study, healthy physically and cooperative during interview process, also mature enough to be able delivering their experiences clearly.

### 2.2. Instrument

The main instrument in this study was the researcher himself. The validation conduct by doing an interview with one parent who has a cancer child at Rumah Harapan Indonesia.

### 2.3. Procedure Data

Data collection have done by researcher used voice recorder following the interview guidelines and make the field notes for any emotion and body languages showed by participant. Informed consent conducted by writer to introducing and explaining the intentions, goals, and benefits of research. Ethical aspects in this study were confidential, fair/did not discriminate, and did not harm any party. The contract for interview each participant was 10-30 minutes or more depend on the agreement with the participant. The interview must be stopped if the participants cannot join the interview until the end and do the contract for next meeting to continue the interview. At the end of the interview, without anything to confirmed with the participants, writer did the termination phase.

### 2.4. Analysis Data

Data analysis in this study used Colaizzi's technique which developed in 1978 began with collecting data and making transcripts based on the interview and then reading the transcript repeatedly to find the keywords from participant statement. After that, the analysis was done by grouping the keywords to make categories and themes. Hereafter the description was made based on the four themes which showed in this study.

## 3. Result and Discussion

There were four themes about experiences family members as a caregiver for cancer children; 1) The physiological needs and need of feeling comfort and safety, 2) Loss/grieving process experienced by caregiver, 3) The ability of caregiver to overcome the obstacles, and 4) Family decision making.

### 3.1. The Physiological Needs and Need of Feeling Comfort and Safety

One of the problem in physiological needs among children with cancer is nutritional imbalance which made nutrition as the basic needs among cancer children. Carbohydrate and protein are the sources of energy needed by children especially children with cancer not only to basic metabolism but also as important components in healing process. The need for fat I cancer children is about 25-30% of total energy. It is

highly recommended for adequate consumption of vitamins and minerals for recovering after surgery and as an antioxidant [3]. Fulfillment of adequate nutrition among cancer children could be a challenge, especially family. [4] said that from around 550% of children who experienced cancer at the time of diagnosis, there were increases of malnutrition prevalence by 40-80% as the disease still developing. Children are often to get the malnutrition due to increased needs during treatment and /or energy limitation. Levine conservation model which prioritizes energy balance can be used to meet the nutritional balance in cancer patients [5]. This is consistent with research conducted [6] which states that the Levine conservation model can be applied to cancer children because this model not only assesses the physiological needs, but also psychological, social, spiritual, and cultural needs.

According to Maslow's theory about needs of feeling safe and a sense of security has a broad meaning in both physiological and psychological aspects. Dian (2018) said that these needs encourage peoples to obtain comfort, peace in life such as getting security guarantee and protection from any kind of distress also freedom from all the threats such as criminalization, war, terrorism, disease, fear, anxiety, danger, riots, and disasters. Someone with inadequate ability to fulfill their needs and did not get a sense of security and protection certainly will feel sad, afraid, and even stress.

### **3.2. Caregiver Experiences the Process of Loss**

Loss is an experience that has been experienced by every individual during their whole life. Since birth peoples have experienced loss and tend to experience it again even though in a different form [7]. Parents get trough several processes of loss starting with the denial phase. In this phase, the first reaction was shocked, did not believe the fact, while the physical reactions showed tired, weak, pale, nausea, diarrhea, respiratory distress, tachycardia, crying, anxiety, and even hopelessness because they did not know what their have to do. The last phase was the acceptance phase where the peoples have already accepted the loss and they can end the grieving process with the ability to overcome the feeling of loss.

### **3.3. The ability of caregiver to overcome the obstacles**

Every person naturally will or already have experienced problems or obstacles in their lives. Various problems experienced by some participants, one of the problem was financial deficiency due to lacking income in the family. [8] optimistic parents will make

them survived and having good resilience from any form of stressors, including cancer suffered by children. Participants in this study said that they can overcome the obstacles optimistically with having social support from mothers.

Social support is information or feedback when someone being loved and cared for, valued and respected, also involved in a network of communication and mutual obligations [9]. This is in line with research [10] which said that social support can bring a positive influence on peoples who suffered. The Foundation where this study conducted, they provide motivation for cancer children, as well as giving a sense of empathy, and attention to them. The existence of social support from this foundation makes children who have cancer become more excited to face their life.

Adequate health facilities are very helpful to conquer the problems that occur in family experience while take care of children with cancer. [11] said that the health care provider helped him to understand the matter about his child's treatment. The explanations which delivered by health care provider will complete with family sharing about their experience because sometimes the information from doctor or nurse hard to understand by the children nor family.

### 3.4. Family decision making

The most family member who acts as a caregiver is a mother. According [12] who said that the role of women in the family is a figure who cares most about the family members health. Mother always gives her best to take care of her family member's health. Because of the natural character of mother, the decision making about taking care of family members also done by mother. This is in line with research entitled "Social support in the process of treating child cancer patients" at 2011, saying that sources of social support for pediatric patients with cancer provided by families, medical teams, and volunteer. But in quantitative terms, parents, especially mothers, are the one who gives the biggest support to the children and other family

## 4. Conclusion

The experience of family members who act as caregiver showed 4 themes include physiological needs such as bathing, feeding, hyperthermia management, and giving drugs. The second theme is needs of feeling of secure and safe such as bringing a child to a health facility. For the third theme that occurred is the feeling of loss by the caregiver. It starts with the denial phase to the acceptance phase. The last theme

showed is family decision making which help family to overcome the problems. The family members also have a strong inner conviction that the child will recover, the support of the surrounding environment with adequate health facilities and decision making are important components during the children treatment. The family as caregiver expected to be able to improve their knowledge with the help of health care provider.

## Acknowledgement

The authors would like to thank their colleague for their contribution and support to the research. They are also thankful to all the reviewers who gave their valuable inputs to the manuscript and helped in completing the paper

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