

Original Research Article

## **Oncology Nursing: A Preliminary Study on Experiences of Mothers of Childhood Cancer Survivors in Kuantan, Pahang, Malaysia**

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### **ABSTRACT**

**Background:** Trends of childhood cancer keep increasing and it has been recognized as the major problem around the world. Childhood cancer survivors and their families had been facing the physical, mental, social and financial problems since the cancer was diagnosed. By exploring the experiences of mothers who are caring for childhood cancer survivors, oncology nurses can contribute to disseminate information between the same group of mothers and other health care providers. There is still a limited explorative study on the experiences of mothers living with childhood cancer survivors in Malaysia.

**Objectives:** The aim of the study was to explore the experiences of mothers living with childhood cancer survivors.

**Methods:** A key informant's interview using semi-structured guided questionnaires was conducted among three Malay house wives, mothers living with a childhood cancer survivor (two Hodgkin lymphoma and one bowel cancer) in the pediatric ward at Hospital Tengku Ampuan Afzan (HTAA), in April, 2015 Kuantan. A matrix analysis was done to find out the theme.

**Results:** The childhood cancer survivors were two girls and one boy ranged in the age from 14 to 17 years old. Three themes emerged from the data that illustrating the mothers' experience of living with childhood cancer survivors. The themes were feelings at the time of newly diagnosed, Challenges and Coping. Each of the themes has sub-themes such as worry, sad regarding their feelings at the time their children have been diagnosed, financial challenges during treatment and also all participants have strong belief in their religion in coping with problems. Moreover, participant mothers disclose that they got mutual understanding from their husbands and also social support from society.

**Conclusion:** By exploring and understanding the mothers' experiences with childhood cancer survivors can provide an insight to all such kinds of parents as well as, health care providers to deliver better quality of care towards these groups. Further understanding of the mothers' experiences with cancer survivors may improve the nurse's ability to provide support and increase awareness of the issues involved caring childhood cancer survivors.

**Keywords:** Experience, Mother, Childhood Cancer Survivors, oncology, challenges, coping.

### **INTRODUCTION**

#### **Study background**

The number of childhood cancer keeps increasing and it has been recognized as the major problem around the world. As reported by Peck (1979) in her study that,

childhood cancer survivors' problem became a less concern compared to the problems of dying children. According to Jones (2012), the cancer disease among children is still recognized as one of the main causes of death in childhood.

According to Malaysia Cancer Registry Report, it is estimated that 37 in 100 000 children aged 0 to 15 years at risk with markedly higher for the boys than girls are developing cancer and 1500 new cases of childhood cancer were diagnosed every year in Malaysia (Azizah, et.al2011).

Having diagnosed with cancer interferes with daily functioning and plans for the future of patient and as well as affected the entire family, especially the parents (Van Dongen-Melmann, Van Zuuren, & Verhulst, 1998). Children diagnosed with cancer become a major stressor to mothers. According to Streisand, Mackey and Herge (2010), the daily necessary management is frequently responsible for mother. Maternal psychological problems were more frequently identified among mothers whose children displayed problematic behavior and emotions compared to those children who demonstrated well-functioning behavior and also the mother feels difficult in caring child with cancer. (Azizah et al., 2011). Streisand et al., (2010), reported that the mothers feel there is no one to share their feelings and keep alone the burden of caring for a sick child.

With the advancement of technology, the numbers of cancer survivors are increasing as the prognosis had been improved. According to Hawkins (2004), most cancer survivors are cured and about 75 % are survived with at least 5-years of extended survival rates in the United States and Western Europe. This condition gives a hope and lessens worries the mothers of childhood cancer survivors.

However, there are still long-term consequences that would be encountered by the mothers. Providing the emotional support adequate for the child, preparing the necessities for seeking treatment such as finding a place to stay and setting date of an appointment, and responsibility to manage the other sibling to handle with the strain of a sick brother or sister are the examples of problem faced by the parents (Ow, 2003). Cancer survivors' children and mothers had

to face an upsetting effect and coping the problem in a long duration when childhood cancer happened or had been diagnosed(Dixon-Woods, Findlay, Young, Cox, & Heney, 2001).Moreover, the parenting experience may become different and more difficult than when raising a normal developing child once a child is affected by social relatedness challenges. Thus, obtaining sufficient support will help mothers to face the challenges during taking care of an ill child.

### **Problem statement**

It is very important to understand the mothers' function in order to understand the best address in the needs of the cancer survivors' children. According to Jones (2012), the preponderance of physical and emotional care to the child can be impacted from gender and role expectations. A few studies have been conducted on the experiences of mothers living with childhood cancer in Malaysia instead of the study more attention paid to childhood cancer survivors. There is no definite evidence from a research focus on mothers in guiding mothers to create approaches to cope with the complex experiences related the diagnosis of their children at the time of the diagnosis, and before their reactions to stress identified (M. Al-Momani, 2013). Thus, this study can help to define the burden of mothers and give a solution to their problems.

### **Significance of the study**

This study is to explore the experiences of mothers through living with childhood cancer survivors. This study is hoped will give benefits to the mothers because the relationship between mothers of a child with cancer is different from the mother who has normal developing children. The experiences of mothers with cancer survivor child can be shared with other parents as one of consolation and courage source with them when faced an upsetting situation.

As the researcher hoped this study can benefit other health care professional and other fields who are providing services

or related to childhood cancer and the parents. Kazak (2004), highlighted that his study can be one of the solution to resolve the parents' and childhood cancer survivors' dilemma as it consists of current empirical reports of psychological interventions for children with cancer and their families and acknowledging the challenges to outline directions for future work in paediatric oncology. Furthermore, the experiences of a mother who has a child with cancer and survived are less studied. Hopefully, through this study, which as an attempt to contribute toward a better understanding the experiences of mothers with cancer survivor children from the diversity of the experiences and perceptions of them, increasing the insight and improving the coping strategies among the mothers of childhood cancer survivors.

### **Research Objectives**

#### ***General Objective***

To explore experiences of mothers who are living with the childhood cancer survivors.

#### ***Specific Objectives***

1. To identify the emotional feeling of mothers with childhood cancer survivors.
2. To determine the long-term consequences of childhood cancer for mothers.
3. To determine the coping strategies of mothers encounter the long-term consequences of childhood cancer survivors.

### **MATERIALS AND METHODS**

A descriptive qualitative research design was used in this study. The participants were chosen among the mothers who have the children with cancer from the paediatric ward and oncology ward at Hospital Tengku Ampuan Afzan (HTAA), Kuantan. To maintain privacy, convenience and comfort of the participants, they were allowed to choose the location of the interview session. Purposive sampling method was used on the basis of known characteristics or experiences. The number

of participants had been determined as three mothers participated based on the scope of objective of this study and inclusion criteria.

This study used the semi-structured interview format during the interview session. The interview session was conducted using Malay and English language suitable with respondents' preferences to help them in better understanding and answering of the questions during the interview session. The participants had been directed to describe their experiences in caring their children through the format and the areas that the researcher perceives as important.

The data collection was started from March to May 2015. The interview session was conducted about 40 to 60 minutes by using semi-structured questionnaire. During the interview session, the conversation was recorded using an audio tape recorder. The interview session was performed in private places or depending participants' preference to ensure the privacy had been preserved. Once finished, the tape recorder was kept in a safe place until the researcher was at home to do the analysis work.

A field note had been kept on recording the observations, feelings, and impression of the participants after the interviews. The data described the physical setting and any nonverbal communication in the field notes that can be used by the researcher as a reminder in order to immerse into the data and the researcher efforts to be self-reflective.

#### ***Statistical analysis***

The interview had been recorded by the audiotape and had been transcribed into verbatim. After the final transcription process had completely done, the transcription had been returned to the participant for the confirmation of the contents. The transcription was checked by the participant and was written as intended.

The qualitative inductive thematic analysis had been used to analyse the data descriptively. In the holistic approach, the researchers viewed the text as a whole and tried to capture its meanings. All the

participants' oral descriptions were read to obtain their feeling. The transcripts were read thoroughly and read repeatedly again to become fully clarified with the information given by the parents. The tape was listened repetitively to ensure the transcripts were apparent in the written word. There searcher highlighted or pulls out statements or phrases that seem essential to the experiences under study. The data that have the same meaning from each participant were highlighted.

Next, the researcher used the detailed or the line-by-line approach. The data were collected continuously through the interviews until data saturation was achieved. The researcher analyzed every sentence. Once themes have been identified, they became the objects of reflection and interpretation through follow-up interviews with participants. Through this process, essential themes were discovered. The data were organized into tables which help to demonstrate common themes and categories. Participants' quotations will also be used as an evidence to support the findings.

## RESULTS

Three mothers who as the participants were interviewed in this study. All participants were Malay, housewives, level of education until Secondary School and living with their husbands. The mother had at least a child with cancer and still survived. The children were two girls and one boy ranged in the age from 14 to 17 years old. Two of them had Hodgkin lymphoma and bowel cancer. Participants' real names were replaced by pseudonyms to protect their confidentiality.

Table 1 Themes and Sub-themes

Themes	Sub-themes
Feelings at the Time of Newly Diagnosed	Worry Sad/ Indescribable/Surprise
Challenges	Financial Relationship between the Husband and Wife Community Perception Hope for the Future
Coping	Strong Belief/ Faith Mutual Understanding between the Husband and Wife Society Support

Three themes emerged from the data that illustrating the mothers' experience of living with childhood cancer survivors (Table 1). The themes are feelings at the time of newly diagnosed, challenges and coping. Each of the themes has sub-themes.

### Theme 1: Feelings at the Time of Newly Diagnosed

The most powerful experience described by the participants' feeling in this study. The participants have to manage their emotions when getting to know the diagnosis of children, during the children received chemotherapy treatments and post-treatments life. Several of emotional feelings of the mothers brought them for seeking out the treatment and to make their children become healthy.

#### Worry

In describing their experiences in taking care of children with cancer, a term such as 'worry', 'I do not know', and 'stress' were a common thread woven through all of the participants' stories:

*"I'm very worried about his condition being stressed. I have asked him, "Are you stressed?" He said: "No, I'm alright Ummy and I'm stressed at school only." (Participant A)*

*"I worry when the doctor claimed he's under pressure, but the only good answer when I asked questions to him." (Participant A)*

*"When the blood result has been released, the doctor told me that my son has cancer. At that time I didn't know much about the blood cancer, but it is only God who knows how my feelings." (Participant A)*

*"At that time, I feel worried, sad and confused. I felt dissatisfied and asking how about the next treatments next to doctor." (Participant B)*

*"I feel nervous, but as the Muslim we have to calm down before receiving any news." (Participant C)*

#### Sad/ Indescribable/Surprise

This sub-theme describes the mothers feel when they knew that their children were diagnosed with cancer:

*"When I heard my son was sick, only God's know and the confirmation of diagnosed from a specialist doctor that my son had a leukaemia. This world feels dark and I feel weak to stand. I asked the doctor, "Did my son could be healed?" Even the doctors said, "Madam doesn't think that your son will be healed, but you should think first how to treat him."(Participant A)*

*"It cannot be told. Indeed, I'm very sad only God knows; especially he is the eldest son and our family hopes."(Participant A)*

*"It was a great and painful hardship. I was surprised and alone."(Participant B)*

*"If possible, I don't want to remember back those memories."(Participant B)*

*"The most unforgettable moment is I cannot accept the fact that my daughter gets cancer."(Participant B)*

*"I thought my daughter just suffers dengue fever and goiter. But during 4 days, the doctor did a biopsy and CT scan at neck site. On the fourth day, the doctor said my daughter had cancer. It's called Hodgkin lymphoma disease. I was surprised."(Participant C)*

## **Theme 2: Challenges**

All mothers mentioned that they face challenges in taking care and managing their children with cancer. They describe what kind of the difficulties that faced by them but some of them took the challenges that not negatively affected her life.

### **Financial**

This sub-theme showed that the mother was concerned about the financial aspects because they had to bear the cost of the chemotherapy treatment. The entire mother mentioned that they faced a financial problem:

*"Of course, it had affected our lives, especially financial support, but we asked help from the Malaysia Welfare Association. In the hospital, they have social welfare to support children treatment. Others forced to settle in HKL for 1-2 weeks."(Participant A)*

*"It is a very hard challenge for us. My brothers and relatives live in Terengganu. Our save money is used for all treatments."(Participant B)*

*"Yes. I asked financial assistance from MAKNA but until now there is no news."(Participant B)*

*"Yes, I have financial problem but I also ask help from hospital social welfare."(Participant C)*

### **Relationship between the Husband and Wife**

The participants mentioned their relationship with husband had conflicts and get influenced by the sickness of the children. In this study, they have the positive attitude or they need and help each other when face the challenges.

*"Sometimes he's supporting me, and sometimes he stressed out. When told there is an infection in the lungs of our son, he gives pressure on me."(Participant A)*

*"He also depressed. He is not stressing how to earn money, but he stressed because forth and back to HKL. He blames on me because our son fell sick. For example "Please sent again your son to the hostel, because of that our son suffer like this". If I know our child will be like this, I won't send him."(Participant A)*

*"I was surprised and alone. My husband not there at that time because he worked in the Immigration Department in Putrajaya. He had to back and forth to the hospital and takes a break. During that time, I can't drive and need to catch bus to go the hospital."(Participant B)*

*"My husband also sad and said that it was a very hard challenge in life."(Participant B)*

*"Sometimes there's tension and stress."(Participant B)*

*"My husband just told me does not cry in front of our child. He did not want the child to be weak as the mother cried in front of her."(Participant C)*

### **Community Perception**

The mothers mentioned that community perception as one a part of the

challenges that had been faced in caring children with cancer:

*"There is some support and there are also looked down on me. For example, what your sins that causes your child very sick."*(Participant A)

*"Neighbors around looking bad for her as abdomen becomes bigger and assume she got pregnant. I feel sad because she only went and back from school and do not have friends since moved here."*(Participant B)

*"There are some neighbors that are not satisfied with our family, but we have to only be patience."*(Participant C)

### **Hope for the Future**

The mothers stated their hope regarding their children's future:

*"I feel the world has been a blackout because a mother's hoped to see the child grew up from a newborn baby to adulthood, from primary to succeed in secondary school."*(Participant A)

*"I encouraged him to socialize, to make friend with others. Regarding doctor's advises, I'm not sent out my son to the hostel and just sent him go to school near my house."*(Participant A)

*"Alhamdulillah I am very happy now as she is healthy; our family is cheerful and still goes an appointment with the doctor."*(Participant B)

*"I pray that she will be someone better and succeeded in the world and in the hereafter. I really hope that no relapses of disease occur."*(Participant B)

*"Sometimes I think if my child died before me, I don't know how I'm going to continue our life as she's the only child in my family."*(Participant B)

*"Every disease, there is a cure. I put all my trust in God and hoping that my daughter healed like other teenagers."*(Participant C)

### **Theme 3: Coping**

The final theme is coping. The participants in this study were coping positively when facing the challenges while taking care of their children with cancer.

### **Strong Belief/ Faith**

A firm belief or faith can help the participant facing the difficulties in caring cancers' children.

*"With mother's intuition and strength given by God, I meet Ustaz in Tahfiz School near my house to ask water for remedy."*(Participant A)

*"Thus, Ustaz tahfiz asked me to bring my son to Tahfiz school to perform congregational pray together to ask Allah's help."*(Participant A)

*"Even though, my son sick, I'm happy because I'm more close to God now."*(Participant A)

*"I always mentioned that people who are given the test, means God love us."*(Participant B)

*"If God did not give us strength, I do not know what happened to me."*(Participant B)

*"When I thought back, as a Muslim is not good to blame fate, contrarily I should be more patience and God will replace with something better."*(Participant B)

*"It feels like there is no difficulty. As the Muslim, we should do a lot zikr (remembrance), prayers and read books as a support and guidance."*(Participant C)

*"Every disease, there is a cure. I put all my trust in God and hoping that my daughter healed like other teenagers."*(Participant C)

*"I feel closer to my God."*(Participant C)

### **Mutual Understanding between the Husband and Wife**

A good relationship between the husband and wife, make the participant become strong and able to face the difficulties in taking care children with cancer.

*"I told my husband about the child's is not quite healthy and he took our son to the nearest clinic."*(Participant A)

*"For example, he was admitted to the hospital for the second time because of high blood sugar during the month of Ramadan, which causes our family fasting*

full one-month in the hospital.”(Participant A)

“The good and bad things in life, we went through together.”(Participant B)

“I advised to help one another because we stayed only two of us and other relatives are far away.”(Participant B)

“My husband just told me does not cry in front of our child. He did not want the child to be weak as the mother cried in front of her.”(Participant C)

### **Society Support**

Most of the participants got moral support from their society while they solve their children’s problems.

“In HKL, a lot of specialist doctor that makes us feel calm and pleased in fact the nurses act like brothers and sister to me.”(Participant A)

“My friends at the hospital give more moral support. Mothers who have children with cancer have a better understanding rather than a normal mother.”(Participant A)

“To solve high blood sugar problem, I also get advice from the mothers who have cancer child.”(Participant A)

“By talking with friends via phone in hospital to get advice and moral support.”(Participant A)

“I asked for help from others to send me to the hospital. At one phase I couldn’t bear, I asked the doctor to provide a letter that made my husband can exchange work place to Kuantan.”(Participant B)

“My neighbor who worked as teacher shares her personal experience. She took care of her mother who and stomach cancer. She encourages my daughter to continue receiving chemotherapy and give moral support to her.”(Participant B)

“In addition, my daughter got motivated indirectly with the words of experience other cancer patient.”(Participant B)

“They also come to the hospital to give moral support to my child.”(Participant B)

“Her siblings and the relatives gave more support to her.”(Participant C)

“I would like to be silent and choose certain people to share stories.”(Participant C)

## **DISCUSSION**

### **FEELINGS AT THE TIME OF NEWLY DIAGNOSED**

The experience of mothers in taking care children with cancer could be the most unforgettable and frightening moment in life. According to Robinson, Gerhadt, Vannatta, and Noll (2006), reported that the mothers of children with cancer encounter more challenges than mothers of healthy children. The participants in this study were found difficulty in describing their experiences that they were going through before the children becomes sick, during receiving treatment until their children healthy again. It seemed the participants were worried and shocked when facing the situation, whereas their children get diagnosed with cancer. McCaffrey (2006) stated that, parents of children with cancer could not express the shock and upset feeling with words as the experience considerable as a grief. Thus, the parents usually are blaming themselves as they could not protect their child from being seriously sick and do not able to carry out the parenting role and responsibilities.

All of the participants noticed that there were signs and symptoms of their child’s sickness, but they could not detect that their children’s health condition were deteriorating unlike the development of the normal growth and development of their children. The participants’ interviews showed that there was not having basic information to help them in understanding cancer at the first time their children had been diagnosed with cancer. A study by Bonner, Hardy & Guill (2006) mentioned that prognosis, treatment choices and etiology of disease are the element of ambiguity that lead the parents’ apprehension increases as a parent and hesitate to make a right decision for the sick child. A study done by Huang, Mu & Chiou (2008) reported that the parents gain

strength to face any challenges when they receive clear information about child illness from a health care professional. Palmer et al., (2011) had mentioned that the health care provider should give time to the parents to convey their feelings and response to their questions and straightforward and open communication as these features were to be found satisfied the parents.

### **CHALLENGES**

The participants in this study stated that experiences of taking care the cancers' children could not be expressed or described profoundly, as an encountering experience itself is part of the challenge in the journey of life.

Three mothers have perceived that financial problem as one of the challenges. The participants were worried that they could not bear the children treatment cost as the treatment needed continuously depend on the types and stages of cancer. Norberg, Lindblad & Boman (2005) stated that the stress level of parents is higher when their child unfinished treatment compared to parents of children in treatment and parents of children off treatment. Miedema, Easley, Fortin, Hamilton & Mathewa (2008), reported that financial insufficiency is a significant burden to parents who cared child with cancer, which includes travel cost, accommodation, medication and medical supplies. The financial strain still becomes a problem for the parents subsequently because the high cost in the treatment cancer survivorship is increasing with medical advances and technology. However, they still could manage the financial aspects of obtaining funds or supports from governmental and non-governmental social welfare associations.

The participants also reported that the relationship between the husband and wife were affected when the children have cancer. The parents get into conflict when their children become sick. Participant 1 and Participant 2 have expressed that their relationship with the husband was distressed, especially in the early stage of a child being diagnosed. Having seriously ill

child gives an impact of parents functioning in the family and the sick child. The stress is higher in a mother than a father who is living with or without a child with cancer (Masa Deh, Collier & Hall, 2012). Norberg, Lindblad & Boman (2005), stated that the mother shows more stress and more bearing of distressing experiences compared to the father as the mother spent more time with the ill child at the hospital. Study done by Syse, Loge & Lyngstad (2010), reported that there is no association between cancer child and divorce probability. The study stated that parents who have a child with cancer have similar divorce rate as parents with healthy children. The bonding between husband and wife will be stronger, especially if the relationship was good at the beginning as they perceive a child's sickness as a common experience a trial of life.

The participants also mentioned that the perception of the community as part of the difficulties that could be facing by the mothers of the children with cancer. The mothers also expressed their concern is that there is unable to predict the future of their children with cancer. Bonner, Hardy & Guill (2006), stated that parents have a deep concern about the long-term improbability especially about the child's future as well as the consequences of previous decision on the child's long-term treatment and achievement.

### **COPING**

In this study, all the participants showed that they are able to adapt their problems positively. All of them claimed that they were able to face the challenges depend on their firm or strong belief in God. A study mentioned by Huang, Mu & Chiou (2008), reported a religious aspect is an important source of gaining strength of a parent with cancer child to have courage facing the difficulties. Instilling faith in coping strategies can alleviate distressing feelings. Palmer et al., (2011) emphasized that spirituality and religion are important elements in parental coping and prayer denotes as a dynamic coping method



compared to an inactive plea in comforting sadness. Maurice-Stam et al., (2008) reported that the bonding between family members exhibit when they face together the experience with childhood cancer. Mitchell, Clarke & Sloper (2006) stated that parents have a good satisfaction in psychosocial support and service provision such as support from staff, medical information and preparation for treatment and support from family members and friends. Hagedoorn, Kreicbergs & Appel (2011) stated that long-term depression can avoid by receiving great support from relatives and friends, as the paramount source of support. Support from health care professionals and social also crucial in lightening the parents' grief course, even many years after the loss. Greening & Stoppelbein (2007) mentioned that parents who using religious coping and hopefulness have less risk for anxiety symptoms. By obtaining an appropriate cognitive appraisal method and social support system able to relief parents' nervousness while they handle aspects of the child's care plan. Ekas, Lickenbrock & Whitman (2010) stated that best family support was accompanied with great optimism. The consequences of caring child with cancer, such as depression, marital stress, parenting strain and negative effect can be diminished by good and firm optimism or hopefulness as well as the optimism can foster life satisfaction, and can increase psychological well-being.

#### **LIMITATIONS**

As a limitation in this study showed that a small number of respondents have participated as it related to individual experience and the researcher has limitation to get a deeper understanding of a mother with survival cancer child as it needs adequate knowledge and experiences regarding the specific area and made the data collection has less delivered to portray mothers' perspectives.

#### **RECOMMENDATIONS**

In terms of practice, nurses should play their significant role in the assessment of the mother and other caregivers' mental health status and behavior in taking care of cancer survivors. The hospital can provide a counseling room for mother expressing her emotion with staff nurse or other health care provider. Further understanding of the mothers' experiences with cancer survivors may improve the nurse's ability to provide support and increase awareness of the issues involved caring childhood cancer survivors. This research is recommended to be conducted on different cultures. It is interesting to determine individual experience with different culture, and the mechanism of coping might differ as influenced by their cultural values when having a child with cancer. This research can be a literature or one of sources to know living experiences with survivors of childhood cancer as a small number of research regarding cancer survivors post-treatment in the hospital.

#### **CONCLUSION**

All three mothers in this study have encountered many challenges in caring children with cancer. The major issue of the mothers of the children with cancer disclosed that they have inadequate financial resources. The challenges in term of marital relationships, community and unknown future of the child are the burden of care in child with cancer.

By exploring and understanding the mothers' experiences with childhood cancer survivors can provide an insight to all such kinds of parents as well as , health care providers to deliver better quality of care towards these groups. Further understanding of the mothers' experiences with cancer survivors may improve the nurse's ability to provide support and increase awareness of the issues involved caring childhood cancer survivors.

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