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## **PSYCHOSOCIAL IMPACTS OF CANCER ON SIBLINGS: QUALITATIVE EVIDENCE FROM INDONESIA**

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### **ABSTRACT**

Living with brothers and/or sisters who have been diagnosed with cancer can cause psychological problems on the part of siblings. This paper aimed to explore the psychosocial impacts of cancer on siblings. This research is a qualitative study using a descriptive phenomenology approach. There were eight siblings who were key informants aged between 8-18 years old, selected through a purposive sampling technique. In-depth interviews were the techniques used to collect data, followed by conducting verbatim transcripts. For data analysis, the Colaizzi's analysis model was applied. The qualitative thematic analyses identified that the psychosocial impact experienced by siblings included the following: (1) grieving process (2) psychological responses; and (3) changes in the sibling's life. This paper suggests that all relevant parties, with particular reference to health care institutions and nurses, should pay attention to information and communication given to the siblings and family so that the effect of children with cancer and the psychosocial impact on siblings in families can be reduced.

Keywords: Children with cancer, Indonesia, Psychosocial impact, Siblings

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### **ABSTRAK**

Hidup dengan saudara laki-laki dan/ atau saudara perempuan yang telah didiagnosis menderita kanker dapat menyebabkan masalah psikologis pada saudara kandungnya. Penelitian ini bertujuan untuk mengeksplorasi dampak psikososial kanker pada saudara kandung. Penelitian ini merupakan studi kualitatif dengan pendekatan fenomenologi deskriptif. Ada delapan informan kunci anak yang merupakan saudara kandung dari anak yang menderita kanker berusia antara 8-18 tahun, yang dipilih menggunakan teknik *purposive sampling*. Pengumpulan data dilakukan melalui wawancara mendalam, diikuti dengan melakukan verbatim transkrip wawancara. Untuk keperluan analisis data, model analisis Colaizzi diterapkan. Hasil utama dari analisis tematis kualitatif menunjukkan bahwa dampak psikososial dialami oleh saudara kandung, termasuk: (1) proses berduka (2) respon psikologis yang mendalam; dan (3) perubahan dalam kehidupan saudara kandung. Penelitian ini menunjukkan bahwa semua pihak yang relevan dengan rujukan khusus ke lembaga perawatan kesehatan dan perawat harus memperhatikan informasi dan komunikasi agar dampak anak-anak dengan kanker dalam keluarga dapat mengurangi risiko psikososial pada saudara kandung.

Kata kunci: Anak dengan kanker, Indonesia, Dampak psikososial, Saudara kandung

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## BACKGROUND

Children living with cancer has long been considered to be a complex problem with a high cost to the family. Several authors asserted that if a child has been diagnosed with only for the child but also for the family members (Woodgate & Degner, 2003). Other scholars pointed out that parents who have children with cancer tend to give a higher amount of care to the affected child, which affects both the physical and mental development of other children in the family (Opperman & Alant, 2003). More particularly, siblings will also experience the challenging situation as individuals who are vulnerable to emotional, psychological, and social developmental changes (Potts & Mandelco, 2012). Siblings of children with chronic illness or disability have been reported to have a 1.6 to 2.0 risk for behavioral and mental health problems (William, William, Raff, Hanson, Stanton, & Hafeman, 2003). Parents may experience a dilemma in caring for their child in the hospital, while leaving the siblings at home. This may lead to another burden on the parents, which may disrupt their attention away from the sick child. Literature about the impact of children with cancer on siblings is very limited in the context of Indonesia. Previous studies have mostly taken place within other countries. This study fills the gap in the literature. This paper aims primarily at exploring the impact of living with children with cancer experienced by siblings.

## METHODS

This study applied a qualitative phenomenological research design to explore the experience of siblings of children with cancer. In-depth interviews with open-ended questions were conducted to explore the experiences of siblings of children with cancer. The interviews took place at participants' homes and hospitals based on an agreement between the researcher and the key participants. The interviews took no more than 45 minutes as suggested by scholars (Basrowi & Suwandi, 2010; Saryono & Anggraeni, 2010). It was necessary to ensure that the key

informants would feel comfortable during the interviews as well as enabling the researcher to build trust in the relationship with the participants.

A demographic information data sheet was obtained from the siblings and verified by the parents. Researchers created interview guidelines based on research objectives, which consisted of four open-ended questions: (1) How did you feel when your brother/sister was diagnosed with cancer for the first time? (2) How do you feel when your brother/sister gets treatment and care in the hospital frequently? (3) Can you tell me any changes perceived by your parents since your brother/sister began being treated in hospital? And (4) What did you do when you were faced with these changes?

Data saturation was achieved after eight key informants selected through purposive sampling were interviewed. The selection of these participants was on the basis of inclusion criteria, such as (1) siblings who had brothers or sisters with cancer; (2) participants aged 6-18 years; (3) participants who had their parents' signature of agreement on the consent form; (4) participants who are able to speak Bahasa Indonesia; (5) participants who could cooperate with the researcher as well as who were open-minded, healthy and able to share her/his experiences.

For data analyses, Colaizzi's phenomenological analysis technique was used. As explained by scholars (Wojnar & Swanson, 2007), the technique comprises of seven steps, including: (1) a process of reading and re-reading the eight transcripts to obtain a general sense of the whole data content related to sibling's responses; (2) extracting significant statements based on each transcript in line with the phenomenon studied which was the impact of children with cancer on their siblings; (3) formulating meanings on the basis of the statements; (4) sorting the formulated meanings into categories, clusters of themes, and themes; (5) integrating the findings of the study into a description of the phenomenon studied; (6) describing the fundamental structure of the description of the impacts on siblings

who live with children with cancer; and (7) validating the researcher's descriptive results by comparing them with the participant's real experiences.

In this study reading and re-reading transcripts was performed to acquire a general knowledge of the siblings' experiences of living with brother and/or sisters with cancer. Then, extracting significant statements aimed at generating information pertaining directly from the psychosocial impacts experienced by the siblings in living with family members with cancer. By formulating meanings, the researcher could illuminate the meanings emerging from the data. Meanwhile, integrating the descriptions with original transcripts was made to identify the shared experiences of all informants with original texts. Describing the themes was by presenting theoretical concepts that emerged from the data and finally, by validating the findings, changes were made in accordance with the voices of the informants. Table 1 presents an example

of the identification process of a theme identified from the data.

Many factors need to be taken into consideration to ensure the trustworthiness of qualitative research. To ensure credibility, the researcher fostered trusting relationships with prospective participants, namely the siblings of children who had cancer, in order to obtain in-depth information. The researcher also clarified the data obtained with the participants (member check). Data saturation was found to have been achieved in the analysis, which strengthens the trustworthiness of the results and the transferability to others in the same context. The result of the study was discussed with experts to certify dependability. The efforts of the researcher to improve confirmability was by involving colleagues/peers and exploring the literature to confirm or justify the existence of new theories that might be discovered and obtained from the findings.

**Table 1. An example of theme identification**

Informant's quotation	Significant meaning	Coding	Theme
I think about it... I realize that it's from God... a disease is from God... we can change it... so, I will not blame S, the parents, and myself... just think about it.. a disease is from God. Don't you agree?	Disease comes from God, we can't change it.	Acceptance	Grieving process
Mom stayed in the hospital, sometimes came to hospital after office hours.. but dad always go home at night after go to the hospital	Mom stay in the hospital, dad go home.	Parents activities changes.	Changes in the sibling's life

**RESULTS**

Table 2 presents the demographic information of the key informants participated in the study. The ages of siblings were ranged from 8 to 18 years old, while patients' ages were ranged from three to 16 years old. There were five males and three female

participants. In particular, all of the participants were siblings by blood of the children with cancer. This relationship called is traditional full sibling, where the participants and the children diagnosed with cancer have the same biological parents. Most of the children were diagnosed with cancer in 2011.

**Table 2. Participant characteristics**

Informants	Sibling's age	Patients' age	Sex	Status of the children in the family	Time of sickness
1	18	16	M	1 from 3	2011
2	16	12	M	1 from 3	2011
3	16	3	M	2 from 3	2011
4	8	5	F	2 from 4	2011

Informants	Sibling's age	Patients' age	Sex	Status of the children in the family	Time of sickness
5	10	16	M	5 from 5	2011
6	11	16	F	2 from 2	2009
7	9	14	M	2 from 3	2012
8	10	7	F	1 from 2	2011

There were three themes identified from the data related to siblings' experiences of the impact of a child with cancer in the family. The themes were 1) grieving process; 2) psychological responses; and 3) changes in the sibling's life. The three themes are explained as follows.

#### *Grieving process*

When a family member recognized that one of the children in the family was diagnosed with cancer, the first stage was grieving. Their sibling would suffer from grief; these are some quotes from the participants:

*"It just sad...the feeling of grief is too heavy knowing that M has that illness..." (P8)*

In particular, most of the siblings explained that they did not believe the issue when they heard that their brother/sister diagnosed with cancer the first time. They believed that their sibling appeared to be in a healthy condition. This implies a feeling of denial on the part of the siblings, as expressed in the interviews below:

*"We do not know anything; suddenly we start to panic, it is a surprise, we never expect that illness before..." (P1)*

*"...Can not believe it, it was a basketball match... after that he was sick, and it was cancer." (P2)*

On the other hand, siblings accept the condition of their brother or sister with cancer. Acceptance is the last stage of the grief process. It is a condition where the sibling starts to accept that their brother and/or sister has cancer. Some of the statements are:

*"...None we could do, it's from God...we could not prevent that.." (P2)*

#### *Psychological responses*

This study revealed that the siblings experience profound psychological responses, including feeling confused and stressed, experiencing empathy, a sense of rejection, jealousy, anxiety, and fear, loneliness, feeling sad and worried. One sibling expressed confusion and stress when faced with situations that are equally important. The situation related to sick children and their future. Here's the sibling's expression:

*"... So confused, yes we're being stressed ... right here, right again exam ... struggling to pass the class ..." (P1)*

Besides, having children who were ill in hospital receiving care led the parents to visit the child frequently and stay at the hospital. The situation led to the siblings feeling empathy towards their parents. However, several siblings revealed a lack of care from their parents and feeling like a neglected child. The following were the statements from the siblings regarding feelings of sympathy and being neglected.

*"Arguably pity... right away from ... I also felt tired." (P1)*

*"... Moreover, when the first time S was diagnosed with cancer, I felt like not being taken care." (P2)*

*"Like a lost child...like being rejected (silent) ... like a lonely man in the roadside." (P6)*

Siblings revealed that the presence of sick children often caused attention to be focused on the sick child. Lack of attention from the parents to the sibling caused the sibling to become jealous, as shown in the following except:

*"Yes, sometimes the S who is primarily, so when S wanted something, it was granted, but I wasn't" (P2)*

Siblings expressed anxiety and fear of the sick brother's condition. The following is an expression from a sibling:  
*"... Somewhere later if something happened to our brother whether he is in good or bad condition, whether he can survive or not." (P1)*

Some siblings expressed loneliness as one of the psychological responses because of not having a playmate and just being alone at home because the sick child was often being treated in hospital. The following is an expression from a sibling during the interview process:

*"Quiet, because mother usually goes to the hospital and nobody at home " (P7)*  
*"I feel lonely if Kn isn't here, no one cry, no one can be disturbed (laughed)" (P3)*

The big difference in the behavior received from the parents caused some siblings to feel sad. The following is an expression from a sibling during the interview process:

*"Sad ... because I can not play with N again ... I can not continue school again ... I can not hang out with friends." (P5)*

One sibling expressed worry about his parents because of limitations in the care of sick children as being incapable of carrying. The following is an expression from a sibling during the interview process:

*"... I am worried about my mother too because she took care of M...I am afraid of my mom cannot carry of M, she is heavy (laughed)" (P8)*

#### *Changes in the sibling's life*

Changes in life are possible not only for parents but also for the siblings. Changes in the sibling's life include changes in family circumstances, changes in activities, being involved in the care of sick children, family management changes, being pushed into maturity, and sibling relationships. Changes in the family situation experienced by the sibling include a change in the parents' behavior. Here's an excerpt from a sibling during the interview:

*"... Sometimes my father is busy to thinking about S, thinking about how to fund for S, thinking about his job, sometimes he is studying alone, hard enough for him to study." (P2)*

Besides mentioning the conditions, the sibling also experienced changes in the role of family members. The first child often needs to carry out the role of parents in caring for and maintaining the health of the other children. The following excerpt was also revealed by the sibling,:

*"Love it ... last Monday until Wednesday sister taught me ...because mother and father were staying in the hospital." (P4)*

The activities of the sibling also changed the school's ranking. Here's an excerpt from the siblings:

*"I ever once skip the class." (P2)*  
*"Last time before M got sick, he got a good rank but now it's rarely." (P8)*

One of the changes in the sibling relationship was a closer relationship to the child with cancer. Here is the statement from the sibling:

*"Yes, before he got sick, he wanted to play with his friends [all the time]... but now he got closer to us." (P2)*

One of the siblings asserted that there was a change in the sibling relationship such as a further distance between siblings. Here is the statement from the sibling:

*"...Our relationship is getting more distant, more individual". (P6)*

#### **DISCUSSION**

Stories from the parents only demonstrated two stages out of the five stages of the grieving processes, which is denial and acceptance. Grieving can be defined as a systematical neuro-psychobiological response in the process of loss (Bruce, 2007). This process is characterized by a distinctive individual process. One team explains that the shock and surprise are two emotions that depict the denial stage (The Psychology Career Center, 2011). The pain, grief and guilt

could also be related to this stage after the shock has taken place.

Denial is a crucial stage which was experienced by most of the children who could not express their feelings well (James & Ashwill, 2007). This stage is experienced by the sibling, within this stage the sibling often feels shocked, panic, and unable to believe the misfortune. This condition could happen if the healthy children suddenly experience the illness. This condition made the sibling feel miserable.

The first response when the sibling heard that their sister/brother experienced cancer is grief. This process is considered as a reasonable reaction because that child expected that the world was a friendly place. This process could happen for months or even years, especially when they have lost their parents and siblings (Maciejewski, Zhang, Block, & Prigerson, 2007). This research also found the same pattern as the above case, where the grief happened because the sibling lost their best friend. The effect of a lost sibling on a juvenile is complicated and indirect (Dallas & Draper, 2005). They would delay expressing their feelings until they felt more comfortable with the situation.

The last stage during the grieving stage is acceptance, a condition where the individual is no longer pressed by emotions or anger. In this stage, an individual could say, "Yes, it's happened, and I'm okay with it" (Pillitteri, 2010). The acceptance stage occurred within the siblings in this study. This happens because the sibling already wants to make peace with the conditions or circumstances that have arisen in the family. Moreover, according to the developmental age of the informants, their cognitive development is in the stage of formal operations thinking which enable them to think reasonably. Due to the existence of counseling and support from various parties, a sibling can go through the stage of acceptance (acceptance), and be involved in the care, attention and be able to work together (Way, 2008).

Research conducted on the sibling revealed that some siblings had

minimal experience of the health problems that occur, which would be confusing (Strohm, 2008). It is also aggravated by a poor understanding of their brothers who are sick. This is consistent with the statement of a sibling that said they feel confused and stressed about this problem that had happened in his life. Siblings revealed that they were confused and stressed about the situation relating to sick children and their future.

The closeness between family members is very influential on the positive response from a sibling. There is a change in the family situation, which resulted from a sibling feeling empathy for the condition that has occurred. Murray (2002) revealed that the experience of a sibling would result in emotional intensity, increased compassion for others, personal growth, supporting others needs and a desire to help others. Empathy results from a sibling who has a desire to help with chores (Murray, 2002).

Research by Yin and Twinn (2004) revealed that the presence of parents who are not paying attention to the sibling would lead them to feel rejected. The sibling also thought that he was unloved and unimportant compared to the sick brother. It was found in this study that the sibling received less attention, felt like a lost child and was not maintained well.

Differences in levels of attention given by parents to their children can cause jealousy (Rauera & Volling, 2007). Things that can cause jealousy from the sibling are the different rules applied to the sick child and the other child. In some qualitative research it was found that siblings understand why their parents have changed, but jealousy is hard to resist or suppress (Wilkins, & Woodgate, 2005). Something similar was found in this study, where the eight siblings understand the cause of attitude and behavioral changes of their parents but still feel jealousy (Wilkins, & Woodgate, 2005).

The research of Barrera, Chung, and Greenberg (2002) revealed that anxiety and fear are experienced by a sibling. Generally, a sibling feels anxious about his health status, worried about being unable to receive treatment, what

happens in the hospital, concerned about the reaction of peers, and health itself. In this study, a sibling felt fear of the ill health of his brother and another wondered if one day her sister would be in a good condition. As well as this, another sibling expressed anxiety for his health, worrying whether his illness was hereditary or not. This study also revealed that the sibling worried about both the parents and sick brother. It appears to be related to the inability of the parents to take care of the sick child.

Siblings reported experiencing profound sadness (Barrera, et al., 2002; Woodgate, 2001b). Sadness is associated with a sense of fear of the death of his brother who was sick, feeling nostalgic for his parents and also nostalgic for his past life. Something similar was found in this study, where the sibling felt sad for the changes that had occurred in his life. Loneliness was also experienced by siblings while his parents were in the hospital. Siblings often feel alone with no friends to play with, and no one to express his feelings to (Woodgate, 2001b).

When one of the family members is diagnosed with cancer, all of the family members are affected. Parents have to change their lifestyle to carry their child to the hospital (Sidhu, Passmore, & Baker, 2005). It causes many changes in normal sibling life (Sharpe & Rossiter, 2002).

The lack of parental attention to the sibling caused a change in school and social activities (Alderfer, Labay & Kazak, 2003). Siblings experienced difficulties in school activities including concentration, memory and learning process (Packman, Greenhalgh, & Chesterman, 2005). The same thing found in this study was that siblings experienced difficulty in concentrating on school activities that decreased their level of achievement at school. Siblings were thinking more about their brother/sister who was diagnosed with cancer.

According to Woodgate the absence of the mother (who accompanies the child with cancer), will force the father and older brother to play the mother's role. It disrupts the sibling's daily activity, by increasing the workload and responsibility

of the father to more than before (Woodgate, 2001b). The same condition found in this study was that the older sibling played the mother's role and replaced the parent's role.

Some literature shows that the parents' behavior towards the sibling influences the quality of the sibling relationship. The relationship between the siblings is unique and different from others. The sibling relationship is affected by each other, not only by the members of a family but also by their friends. The same condition was found in this study. A child with an excellent relationship with the child with cancer would have good behavior. Also, the relationship between children changed for the better. The most significant change was a closer relationship. Another finding in this study was an increasingly distant relationship due to an already poor relationship between the sibling and child with cancer (from the beginning).

In general, the closer the sibling's age gap, the more significant change between them, especially emotional characteristics. The bigger the sibling's age gap, the more dominant the influence of the parent would be than the sibling (Salmon & Shackelford, 2011). Differently from this study, the author found that the more significant the age gap among siblings, the stronger the emotional characteristic found. This occurred from some of the informants in this study where adolescents who had a more mature way of thinking and were more aware of their siblings condition.

## CONCLUSION AND RECOMMENDATIONS

It is expected that this study's results could be a source of support to the patients and the families. Lack of attention and information given by the parents towards siblings should become a nurse's attention. Thus, the nursing care provided was not limited only to the child who was sick, but directed to the whole family, especially the sibling. The results of this study are also expected to expand the scope of pediatric nursing practice, which is not only focused on the sick child and

the parents but also the sibling of a child with cancer.

The first time the siblings heard that their brother had cancer, the first response was that the sibling experienced the grieving process, such as: feeling sad, feeling of disbelief/denial and ultimately experiencing the current condition (acceptance). The deep psychological response of the sibling arose from changes that happened in their family life. Perceived psychological responses included feeling confused and stressed towards problems that were experienced by sibling and child that was sick, feeling sympathy and worry for parents, loneliness, sadness, feeling of being rejected and jealousy. Siblings have needs that should be fulfilled. These needs include the need for information and support from various parties. Siblings also have reasonable expectations from their sick brother and from their parents.

Nursing education is expected not only to provide information about the impact of hospitalization on a sick child and their parents but also the changes that can occur in the sibling. It can be used as an essential source of information for nursing education, especially pediatric nursing in the context of the family.

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