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PSYCHOLOGICAL EXPERIENCE OF CHILDREN WHOSE PARENTS HAVE CANCER DISEASE IN BATAM

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ABSTRACT

Cancer is the second leading cause of death in the world. Cancer is a large group of diseases that begin in all organs in the body, when the cells in the body are abnormal and uncontrollable, the cells will attack adjacent body parts. In Indonesia, the highest cancer cases are in the Yogyakarta area of 4.86%, in the Riau Islands the incidence of cancer is 70.1%, being diagnosed with cancer not only had a detrimental impact on patients, but had a substantial impact on various aspects lives people they love, one of them was a child. Children who live with parents suffer from cancer experience psychological disorders such threat of losing their parents, changes in daily activities. The aim of this study was to explore the psychological experiences of children whose parents have cancer. Technique sampling was Snowball sampling with 10 participants. Qualitative research method with semi-structured interview design. Results five themes were identified, Care for the condition of sick parents, Fear of loss, Coping strategies in life transitions, Getting a support system, Gaining life lessons. Conclusion was the children experience various negative feelings, but they try to be able and take various actions for their parents to stay healed.

Keywords: Experience, Psychological, Children, Parents, Cancer

INTRODUCTION

Currently the world is facing health problems which are marked by an epidemiological transition, namely a shift in health problems. Palliative care in the specialization of oncology is needed when the disease is incurable, in which case the value of quality of life will be critical. Palliative care is different from medical treatment in other fields of disease, this is because in the field of palliative care it requires care that can clarify the meaning of life and face death as a reality that must be experienced by every human being. The role of palliative nurses is very much needed by the patient and the patient's family, so that the patient's quality of life is further improved, reducing the patient's suffering, and strengthening in terms of spirituality and the values of beliefs held by the patient and the patient's family. Palliative diseases have many types that people often don't know about, one of these types of diseases is cancer (Riskasdas, 2019). The World Health Organization World Health Organization, (2022) states that cancer is the second leading cause of death in the world. Cancer is a large group of diseases that starts in all organs in the body, when the cells in the body are abnormal and uncontrollable, these cells will attack adjacent parts of the body and even spread to other organs. Deaths from cancer account for 10 million deaths in the world, the World Health Organization, (2022) states that cancer cases that occur in the world include Breast Cancer (2.26 million cases), Lung Cancer (2.21 million cases), Bowel Cancer colon and rectum (1.93 million cases), Prostate Cancer (1.41 million cases), Skin Cancer (Non-Melanoma) (1.20 million cases), Stomach Cancer (1.09 million cases). The common causes of death from cancer are lung cancer (1.80 million deaths), colon and rectum cancer (916,000 deaths), liver cancer (830,000 deaths), stomach cancer (769,000 deaths), breast cancer (685,000 deaths).

In Indonesia, based on data (Risikesdas, 2019), the highest cancer cases were in the Yogyakarta area of 4.86%, data on cases of cancer incidence and cancer deaths that occurred in Indonesia were Breast Cancer (19.18%), Cervical Cancer (10.69%), Lung Cancer (9.89%), Colorectal Cancer (9.88%), Liver Cancer (6.08%), Nasopharyngeal Cancer (5.92%), Non-Hodgkinlymphoma Cancer (4.66%), Leukemia Cancer (4.44%), Ovarian Cancer (4.38%), Thyroid Cancer (3.78%).

In 2019 the incidence of cancer in the Riau Archipelago was 70.1%, the number of patients who screened for cancer was 10,429 people and those who were detected with cancer were 252 people, (Riau, 2019), the incidence of cancer that occurred in one of the hospitals in the Archipelago Riau

in 2022 a total of 127 patients, the incidence of cancer in the city of Batam is 15 patients namely people who are at the Catholic Church of Mary Mother of Perpetual Helpers. The age range of patients with cancer in Indonesia is 55-64 years Risikesdas, (2019) while in the Riau Archipelago it is 30-50 years as many as 183 people have been detected with cancer, (Riau, 2019).

Factors that cause cancer are tobacco use, alcohol consumption, unhealthy eating patterns, lack of physical activity, air pollution. 13%. Globally diagnosed cancers are associated with carcinogenic infections, including *Helicobacter pylori* human papillomavirus (HPV), hepatitis B virus, hepatitis C virus, and Epstein Bar virus. These things make the patient's condition worse and have an impact not only on the physical part, but also on the psychology of the patient and the patient's family, World Health Organization, (2022), Being diagnosed with cancer does not only have a detrimental impact on the patient, but has a substantial impact on various aspects the lives of their loved ones, one of which is their child. In European countries around 4-7% of young adults aged 26-45 years have experience living with their parents who have cancer, and they report experiencing psychological and psychosocial disorders such as anxiety, depressive symptoms, low self-esteem, threats of loss parents, changes in Chen's daily activities (2018). Other impacts felt by them include not telling their feelings to anyone, lack of concentration in carrying out activities, fragile quality of life, wasting a lot of time looking after their parents so that they are hindered in carrying out other activities Hauken (2018), Children who belong to the age group Young adults and older tend to experience high anxiety about the impact of illness on their parents. Several studies say that children whose parents have cancer have negative emotions, social problems, cognitive behavior, and feelings of guilt about themselves (Huang, 2020).

Research from McCaughan, (2021) suggests a solution to help children who have parents with cancer, namely parents must include their children in the EOL (End Of Life) experience, when parents who have cancer feel healthy enough, the parents try to be involved in daily life of their children, listening to children's sadness and providing support in the form of love for children. Meanwhile, Inhestern & Bergelt (2018) argue that nurses play a role in providing parents with the opportunity to carry out their role as parents assisted by their healthy partners. With the hope that parents will not only share their burden and sadness but can identify their family as a support system. According to Huang (2020), parents should not underestimate their child's feelings but rather help their child to understand and deal with the child's feelings. Healthy parents as well as grandparents must participate in interacting and understanding the child's feelings.

Research from McCaughan, (2021) suggests a solution to help children who have parents with cancer, namely parents must include their children in the EOL (End Of Life) experience, when parents who have cancer feel healthy enough, the parents try to be involved in daily life of their children, listening to children's sadness and providing support in the form of love for children. Meanwhile, Inhestern & Bergelt (2018) argue that nurses play a role in providing parents with the opportunity to carry out their role as parents assisted by their healthy partners. With the hope that parents will not only share their burden and sadness but can identify their family as a support system. According to Huang (2020), parents should not underestimate their child's feelings but rather help their child to understand and deal with the child's feelings. Healthy parents as well as grandparents must participate in interacting and understanding the child's feelings.

The results of a preliminary study conducted on 4 children whose parents had cancer in one of the cities of Batam, Riau Archipelago by asking several questions. According to these children, they had never been asked by anyone about their experiences with having a parent with cancer, and they felt guilty because they could not find medicine that could cure their parents' illness. Sometimes they pretend to be strong so they don't look sad in front of their parents but inside they feel broken and sad that cannot be expressed in words. But they accept their parents, and always pray and hope that miracles of healing can occur in their parents.

Based on the phenomena that occur, it can be seen that no one has paid attention to the condition of children whose parents have cancer, while it has been seen that children experience some unusual effects on themselves. This can be said because there are no reports regarding research in Indonesia, especially one city in the Riau Archipelago that specifically addresses the experiences of children who have parents with cancer. Researchers see that it is necessary to raise this phenomenon as a research basis to find out specifically the personal experiences of children whose parents have cancer.

RESEARCH METHODS

A. Research Design

The research design used in this study is a qualitative research method. Qualitative research is a type of method to be able to explore, describe and understand the meaning of a number of individuals or groups of people who are considered to originate from social or humanitarian issues. This research process involves important efforts such as asking questions and procedures, collecting specific data from participants Creswell, (2021).

B. Research Participants

Participants are people who can provide the information needed by Creswell (2021). The selection of participants in this study used the Snowball sampling technique. Snowball sampling is serial reference sampling defined as a non-probability sampling technique in which the sample has properties that are rarely found. It is a sampling technique, in which existing subjects provide referrals to recruit the required sample for research studies. The samples taken were children whose parents had cancer.

C. Location and Time of Research

This research was conducted in Batam, Riau Archipelago to be precise at the parishioners of the Maria Bunda Perpetual Parish Catholic church, where researchers conducted research on children whose parents had cancer.

D. Research Instruments

1. Semi Structured Interview

Researchers conducted face to face interviews (face-to-face interviews) with participants. Interviews like this require open-ended questions designed to elicit the views and opinions of the participants (Creswell, 2021).

2. Recorder

This study also uses a recording device such as a cell phone as a data collection tool to make it easier for researchers to recall what the subject has said. Researchers used the Record tool with the subject's permission. This is in line with Creswell, (2021) who said that wherever possible interviews need to be recorded and transcribed word for word so that it is not wise for researchers to rely only on memory.

E. Data Collection Procedures

The data collection method is the method used by researchers in collecting research data (Creswell, 2021), namely:

1. Licensing stage

a) Submitting the title to supervisor I and supervisor II

b) Request a preliminary study from Study Program to request data, data on patients with cancer diagnoses along with data on their children.

2. Data Collection Stage

a) After obtaining patient data with a cancer diagnosis along with child data from the patient

b) Researchers conducted a preliminary study

c) The researcher conducted interviews with the patient's children who had been determined by the sample criteria

d) Researchers provide explanations to prospective respondents about the purpose, benefits of research conducted, and the interview process.

RESULT

A. Characteristics of Participants

The participants in this study were children whose parents had cancer, as many as 10 participants including 7 girls and 3 boys who participated in this study. The age of the participants varied with the youngest being 20 years old and the oldest being 34 years old.

B. Interpretation of Research Data Analysis Results

Based on the results of interviews conducted, researchers have identified five themes related to the research objectives of these themes including caring attitudes towards the condition of sick parents, fear of loss, coping strategies in life transitions, obtaining support systems, obtaining life lessons.

Theme 1: Caring attitude towards the condition of a sick parent.

The attitude of caring about the condition of parents who are sick is related to the participants' initial knowledge of the illness experienced by their parents, while the form of caring attitude from the participants is trying to know the real condition of their parents and being affectionate towards their parents.

This can be seen from the following expressions:

a. Trying to find out the real condition of parents.

"There was a question, they said if the dose was increased so that the healing process would be faster" (P1)

"Yeah, I've also often heard that people are sick with cancer, it won't be completely cured, if it's relieved the doctors also say every time they take treatment, this only relieves it can't cure" (P3) her heart,...and indeed it turned out that the medicine was aimed at the heart that's why the mother's heart was beating really strong" (P4)

"...then I googled it, and it turned out that it was a chronic disease, so I felt more and more afraid that I always called or asked the nurse why it got so painful..." (P6)

"Every day I try to find information on colon cancer, I learn, after that I try to find treatment" (P8)

b. Be loving parents

"I'm the one who takes care of my mother, starting from bribing, cooking food... I'm the one who always delivers and accompanies mom... When it comes to housework, I do the work, from washing to cooking... I just really hope that my mom gets better, because previously it was cured when the cancer was in the uterus..." (P1)

"In that case, my sister and I always take turns because we work together, so we arrange the schedule for who can take mom, always taking turns between me and my sister...by taking care of mom when I come home from work... mom will definitely recover, especially since mom's breasts are already on. Lift one side so I have to always take care of my mom...even though it's a pandemic and I have to go back and forth between chemo and other treatments, the three of us are optimistic that mom will get better" (P2)

"At home, my father and mother, if my father has a relapse, my mother will tell me that we will come directly to the hospital, we take turns at the hospital, according to the schedule... I hope that the disease will recover" (P3)

"...then look at mom, tell me how come mom isn't sleeping yet, I say sleep quickly if mom doesn't sleep I won't sleep... since mom is sick, just playing on standby with her cellphone so that she has friends... Yes, it's like staying by the side, what do you want to eat, What do you want to cook... yes, when you come home from work, iron it, don't iron it later" (P4)

"There are three of us, I'm three siblings, right? My brother, me and my sister immediately share the task... so we're children, okay, mom, what do you need, what do you need, mom..." (P5)

"and I'm the one who always takes care of it,... we already know mom's condition is like that so we don't have a loud voice that makes us scream" (P6)

"It's just that since mom got sick, I'm the one who spoiled mom like that, we divided the tasks" (P7)

"I have to find out what mom feels when I'm not working, I focus on accompanying mom, ... Yes, I'm the one who waits for and accompanies mom, from the beginning mom comes in until she leaves" (P8)

"I used to make mama's juice, I always cook it, I usually eat it for bribes... so every time I come home from work I take care of mom to eat and share the juices,... I focus on taking care of mom just like before" (P9)

"... what else does mom have to go to chemo and undergo treatment, I'm used to it, but if I have shifts so I can accompany mom and take care of mom when she's on chemo..." (P10)

Theme 2: Fear of losing

Fear of losing is the impact of the problems experienced by the participants in the form of feelings, reactions, and thoughts of the participants in dealing with the problems they are experiencing. The emergence of fear of loss comes from participants who describe sadness, and keep their own feelings.

a. Sadness

"...when I see mom I'm sad because mom is in pain every day, she has trouble sleeping, she eats less and it's hard to eat, ... There is a feeling of sadness, when compared to me it's more sad, it's

big, but there's embarrassment because of the shame too..." (P1) "Well, I'm sad and always think this stuff can be cured or not, because I'm typical that I always think about anything and it's definitely carried over wherever I go... I usually cry in the bathroom when I take a shower because it's delicious while take a shower..." (P2)

"...the cost of treatment is huge if we've already had cancer, that's what we're also worried about, ... but what if I'm sad to the point of depression isn't there, but really sad..." (P3)

"I feel really confused, because if cancer doesn't last long,... mom is just here, it's not legal like that, we still need a mother,... really hopeless, if mom isn't there, I also don't have to be there. , until that much" (P4)

"... without oxygen for half an hour, so I had to experience seeing this dead or alive mother, it was like I left the room and could only cry silently, I was afraid of losing my mother, to the extent that I didn't want my mother to be sick, seeing my mother in pain felt like us. it also hurts..." (P5)

"Well, when I'm sad,... I'm really devastated,... I once left my mother's room and cried in the bathroom because I couldn't bear to see my mother's condition" (P6)

"Mmmm, if you feel sad... when you leave the doctor's office, then I cry sadly... I'm afraid that my mother will suddenly leave me... sad for sure, because I was shocked, right... Mom, you have to see when my name was announced. graduated, and you also have to see your brother graduate" (P7)

"...sad to see mom, ... on the other hand I'm afraid of losing, on the other hand I'm sure the operation will go well,... I often cry, especially at the beginning when I know mom is sick I go to work crying all the time" (P8)

"If you feel sad and really devastated, of course... I immediately thought this disease could be cured or not... I don't want to lose my mother... and I have to see my mother like that, it feels really broken" (P9)

"Well, as a child, I was sad, and I thought about whether I could get through everything like that,... I went out and cried until I really calmed down" (P10)

b. Cover up the feelings experienced

"No, I keep everything to myself, no one should know about the problem I'm facing,... I never complain to my family, and mostly I just keep it to myself" (P1)

"...if I go to mom I never complain,..." (P2)

"...because it's impossible to try your luck with your mother later on it will add to your burden...she's the only one who told me, but I didn't tell her,...I'm also the type of person who doesn't like to compete with my family" (P4)

"I never want to show that I'm sad in front of anyone,... but I'm mostly self-conscious when I complain to my brothers and sisters, I'm afraid they will think about it" (P6)

"No, not in front of mom. it's just that the crying isn't like when we're crying alone, ...often crying alone in my room or at the mall I'm walking, I'm wearing a mask so I just cry while walking without anyone knowing" (P7)

"I cry when I'm alone, no one knows and no one sees me cry" (P8)

"I'm not complaining to him, because I know he will also drop... but again, I don't want to tell anyone but myself" (P9)

"... because I don't want my mother to see me cry... because I don't want other people to know that I have a lot of problems like that" (P10)

Theme 3: Coping strategies in life transitions

Coping strategies in life transitions are participants' ways of dealing with the problems they experience such as trying to be strong, and doing positive activities, this can be seen in the following statement.

a. Try hard

"Stay strong, life goes on, and carry out daily activities normally to be able to achieve what we want" (P1)

"You have to stay strong, don't be weak, you can be sad, but you have to do what is your task" (P2)

"Don't give up because after all, it's our own parents, ...life must be lived, if you don't live it, how will all of this happen later" (P6)

"Life must also go on no matter what happens, we must be sure that it's all part of God's plan" (P8)

"I still keep our spirits up, and never give up let alone depression, because if we are weak how can our parents need us" (P9)

"For me personally, you have to be strong and you can't give up, because parents need support from children too, right, if there is no support from children, who else will they support?" (P10)

b. Do positive activities

"Usually I study or read books because I also freelance as a jockey, so I do work,... At least I clean the house, meet people, have discussions with people outside, and hang out a lot" (P1)

"watching to the cinema, I definitely don't think about it right away" (P2) "We like to give new clothes to dad, when it's payday we buy delicious food, ... buy sandals buy caps but we know it doesn't mean anything to him" (P3)

"Have time alone what I want to do, whether it's me doing sports or whatever, .. I prefer to be alone" (P5)

"I usually play futsal because I like futsal too, so when I'm really too late I play futsal" (P6)

"When I usually listen to music and go out looking for wind, it's like going to the mall, and meeting friends, that's all" (P9)

"I'm used to cooking or I'm alone in the room for about an hour or two" (P10)

Theme 4 : Getting a support system

Getting this support system is something that is obtained by participants to be able to overcome the problems they face, the support system is in the form of participating parents and from other people such as other family and friends of participants.

a. Support from parents

"He has no such thing as complaining, crying, he is a tough person, tougher than us, so his mother's words of advice are better than us" (P3)

"Mama accepted it with joy and it seemed like she didn't feel afraid to do it, just be happy and happy, that's what I saw mom, and it turned out that the energy was transferred to me" (P5)

"Mommy is like telling me to calm down like that, and I keep saying why I was immediately sentenced to cancer, but my mother said no, the doctor can say that but God's power is different" (P7).

b. Support from friends or relatives

"Yes, a visit from a church..." (P1)

"Even church members, there are visits to give motivation, pray together for mama, so there's a lot of enthusiasm coming from everywhere" (P2)

"Yes, I am also very grateful to have friends who are as solid as me, when they know they have made the decision to come home" (P4)

"Yesterday we had the chance to run a fundraiser...and Praise God until now, not until yesterday, only 3 months of doing it, there were almost 200 million donors, 198 million donors, whom I don't know, and that was a very valuable experience for our family because we were able to meet so many people" (P5).

Theme 5: Acquiring life lessons

Obtaining life lessons is a lesson that can be obtained through the experiences experienced by each participant, including getting life lessons. The life lessons that can be learned include participants getting closer to God, because participants always bring in prayer every development experienced by their parents and their hopes for the future for their parents, these things can be seen through the following statement:

a. Become closer to God

"I usually pray,... for praying I usually just stay in my room..." (P2)

"It's like the main hope is just prayer, that's all there is nothing else, ... because if we don't pray our family and our minds will go everywhere" (P4)

"I can only pray Lord Jesus help, Lord Jesus help,... well in the end we can only pray,... Praise God we pray praises after that I can't stand it all can't speak" (P5)

"I can only hold mom and pray,... I always pray"
(P6)

"At that time there was nothing specific, most of all we just prayed" (P7)

"I pray more... Yes, I pray more... even when I cry, I have the time to pray" (P8)

"The same at night I usually pray" (P9)

"...if I don't hide it, I pray" (P10)

DISCUSSION

1. An attitude of concern for the condition of a sick parent

The attitude of caring for the condition of parents who are sick is related to the child's initial knowledge of the illness experienced by his parents, while the form of caring for children is trying to find out the real condition of the parents and being loving to the parents. This is in line with research from Thastum, (2008) which suggests that children whose parents are seriously ill must be given adequate information about their parents' illness so that children know for sure what happened to their parents.

2. Fear of losing

Fear of losing is the impact of the problems experienced by children in the form of the feelings, reactions, and thoughts of the participants in dealing with the problems they are experiencing. The emergence of this fear of loss comes from children who describe sadness, and keep their own feelings.

This is in line with Huang's research, (2020) regarding the concerns of children whose parents have been diagnosed with cancer, in this study children experience deep sadness when they find out their parents have been diagnosed with cancer, they tend not to be able to imagine the severity of the disease, this is in line with research results when children experience grief because of parents they experience diseases that they did not expect their own parents to experience.

3. Coping strategies in life transitions

Coping strategies in life transitions are a way for participants to deal with the problems they experience, such as trying to be strong and doing positive activities. Coping is defined as a cognitive and behavioral effort to manage certain external and internal demands that are considered to burden one's resources, (Thastum, 2008).

4. Get a support system

Getting a support system is a consolation or something that can be obtained from children to be able to overcome the problems faced by the support system. Support is considered important in dealing with various aspects, including illness. Support is needed in specialized health services

in the environment and community, with the support provided, children who experience problems will feel positive thoughts within themselves, (Schiena, 2019).

5. Get life lessons

Being closer to God is something that is learned through the experiences experienced by each child, because children always bring in prayer every development their parents experience and their hopes for the future for their parents. Lin, (2021) revealed that children's awareness of the weaknesses of their parents and understanding of their parents' illnesses will encourage children to get used to things that did not happen before and be more accepting of the circumstances that do occur.

Conclusion

When parents are diagnosed with cancer, children experience various negative feelings, but they try to be able to deal with it and they try to take various actions for their parents to get well, even though they have carried out various activities that make them temporarily lose their minds, but things it can't solve their problem.

They get many things in going through the problems they face, but still they need other people in their life to be able to get out of their uncomfortable zone, not a few of them get various supports from both parents and other people, this is one of the solutions that make them feel a little less suffering in feelings. Because with the support given they feel that there is still hope in their lives to be able to go through the problem until they get good results.

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