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Perceived Barriers and Experiences of Parents in Performing Oral Care on Children Suffering from Cancer: A Qualitative Study

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Abstract--- *Oral hygiene is one of the factors associated with dental problems, a major factor in preventing oral infections and systemic complication prevention. This study aims to explore the perceived barriers and experiences of parents in performing oral care for children suffering from cancer. The study sample consists of 16 parents of children with cancer who live in special shelters for children with cancer who have homes very far from the hospital. This study used a qualitative design through semi-structural phenomenological interviews. The data were analyzed by Colaizzi. The perceived barriers experienced by parents come from external and internal factors. External barriers originate from the condition of the child during hospitalization as related to the equipment installed, for example, the IV line, oxygen mask, etc. Internal barriers are strongly associated with concerns about the possibility of bleeding if the child is given oral care. Health education about oral care can provide an understanding and information about procedures appropriate for oral care methods for children suffering from cancer.*

Keywords--- *perceived barriers, oral hygiene, oral care, children, cancer, and parent*

I. INTRODUCTION

Cancer in children increases every year. Cancer is a leading cause of death globally [1] and has become the second most common cause of death in children, after accidents [2]. There are about 110 to 130 cases per million children per year, of which 80% of cases of childhood cancer occur in developing countries. Indonesia, as one of the developing countries, has a child cancer incidence of 11,000 per year [3]. The incidence of cancer that affects children (<20 years) reached 263,000 cases globally [4]. Indonesia has 13.2 million, or as much as 6% of the population (Data Center MoH RI, 2015). The prevalence of the incidence of cancer in Indonesia in children under 1 is 0.3%, and 0.1% in children aged 1-4 years and 5-14 years [1].

Chemotherapy is one of the continuous treatments for children with cancer and has both therapeutic and side effects [5]. Children with cancer undergoing chemotherapy treatment are at risk of mucositis and dental caries [6]. Oral hygiene

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is important to increase comfort for cancer patients [7]. It is one of the factors associated with dental problems, a major one in preventing oral infections and systemic complication prevention [8][9] [10]. A study revealed that 38.3% of parents reported that their child did not carry out oral hygiene [11]. Based on research, the frequency of children with leukemia brushing teeth at morning and night was 30%, mornings only 46.7% and at night alone 23.3% [12]. Children need their parents' help to maintain hygiene and oral health because of a lack of knowledge and capabilities [13]. It takes parents' confidence and assertiveness to teach and get children to perform oral hygiene correctly [14].

Parents encounter various barriers in implementing oral hygiene in cancer children. The greater the barrier, the smaller the possibility of action to be performed by parents in oral hygiene for their children with cancer [15]. The parents' attitude and behavior in raising children's oral health affect the child's habits to perform oral hygiene [14]. Self-efficacious parents encourage behavior that is more effective in child cancer when parents are confident in their abilities, including oral hygiene behavior, [16]. This study aims to explore the perceived barriers and parents' self-efficacy in oral hygiene in child cancer.

AI. METHODS

Design

This study was a qualitative research through semi-structural phenomenological interviews.

Participants

The participants in the study were 16 parents of children with cancer who live in special shelters for children with cancer who have homes very far from the hospital. Children are permitted to stay with their parents for several weeks while waiting for the next chemotherapy round. Researchers used a convenience sampling technique. The inclusion criteria in the selection of the participants were parents who have children with cancer aged 1-6 years, diagnosed at least one year, and able to communicate fluently.

Instruments

Researchers themselves are the tools of data collection in qualitative research methods. The researchers used a semi-structured interview to gather information from the participants. The questions were about the parents' experience in performing oral hygiene to children. Data collection tools in qualitative research include an interview, voice recorder and field notes.

Procedure

The study began with the preparation of proposals and was followed by material testing by experts to provide clarification and suggestions. The study was conducted from February to July 2019. Data were collected through semi-structured interviews and field notes. Researchers conducted observations by field notes covering the atmosphere of the place during the interview. Interviews were conducted face-to-face with participants in collecting information through the frequently asked questions. The data collection procedure began with a preparation phase, which involved administering licensing for research participants who met the criteria. After the researchers asked for the participants' consent, the data were collected through semi-structured interviews and field notes. Data analysis and results were obtained and then discussed and conclusions were drawn from the research.

Data analysis

Data analysis used the Colaizzi method which allows for clarification related to the participants through the analysis of the results. Furthermore, Colaizzi also allows for changes in the data analysis based on clarifications that have been made to the participants.

BI. RESULT

This research resulted in seven (7) themes based on particular goals. Here are the results and discussion of each theme:

Theme 1: Perceived barriers to perform oral care

Results from the study indicate two sources are identified, external and internal barriers.

External barriers

External barriers include barriers that come from the children and the environment. The participants in this study said that the barriers from children were in the form of verbal denial, rejection by a physical response such as fussing, crying, or nausea, as well as the physical condition of children as teeth shaking, oral mucosa easily bleeding and ulcers. The participants disclosed the following:

"Maybe it's hard. Sometimes s(he) would s(he) don't "(P3, P4, P5, P6, P10, P13, P16)

"He was crying, he did not want to open his mouth" (P1, P7)

A total of five participants in this study revealed that the hospital environment may inhibit parents from performing oral hygiene because many things make children feel uncomfortable and the child must undergo a medical procedure, such as bed rest due to inserted IV-line or an oxygen mask that does not allow for oral care.

"When she was in hospital, she did not want (brushing teeth)" (P6, P9, P10)

"I could not brush her teeth, her hand was in contact with the infusion so I could not get it off" (P13)

"He (she) used an oxygen mask for one week, I never brush his (her) teeth" (P14)

Internal barriers

The internal barriers were parents' psychological attitudes. Parents said that felt anxious and afraid of their children's condition.

"I feel worried anyway, because sometimes when I brush her teeth a little blood comes out" (P2, P8, P9, P10)

"Feel worried and fear" (P8, P10, P11, P12, P16)

Theme 2: Sources of the experience of parents to perform oral care

Participants said they received health education about oral care from health workers and mass media, such as TV, YouTube.

"I am often asking the doctor, often looking for information" (P13, P14)

"Yes, sometimes I see on YouTube, find the right information which many have written about" (P2, P5)

"Ya, on the TV, promotional toothpaste for children that's good" (P7)

Theme 3: Support for parents to perform oral care

There were various kinds of support, such as information and instrumental. Eight participants got support information from health providers or friends in the form of advice and suggestions, as follows.

"Yes there are, the dentist in the health service said to brush your teeth to prevent caries. Sometimes it motivates her" (P2, P12)

"Yes, sometimes I question my friends to gain experienced advice" (P8, P11)

Participants received support in the form of toiletries and toothbrushes from the shelter home, as expressed by the participants as follows.

"When they first went there They had to buy their own, yes, but now I get them from here every month" (P2, P3, P4)

Theme 4: Benefits of oral hygiene

The perceived benefits of oral hygiene were never having a toothache, clean teeth not black, and not hollow.

"Thank God, never toothache" (P4, P14, P15).

"Yes, teeth were clean. Now, also, his teeth are slightly brown-black." (P8, P10, P12)

"Yes nice, there was not perforated, perforated, but, yes, it was not regular to brush their teeth" (P3, P14).

Participants revealed that they no longer worried about the condition of their children's teeth.

"Yes, well, she (he) never toothache, yes, not perforated. His condition is getting better, the first perforated teeth. Thank God, I never worried anymore" (P14, P15).

Theme 5: Parental confidence in performing oral care

Parents kept trying to perform oral care on their children due to the parent's role and hoped for healing.

"Yes, I always do brush my child's teeth, never say tired for children" (P1, P2, P15).

"Yes, that the parent expects that when they are essentially cured of the disease, they will be healthy. It is no longer a problem. The condition is stable" (P15, P16).

Theme 6: Parent preparation to perform oral care

The participants in this study revealed that, before oral care, there were preparations made starting from the selection of the tool used by the child and preparation tools. The tools used to perform oral hygiene were a toothbrush and toothpaste for children, silicon toothbrushes, gauze, coarse washcloth, or fabric shirts for children brushing their teeth.

"Brush the teeth with baby toothpaste, yes, that's usual for infants (children)" (P2, P3, P4, P5, P6, P7, P8, P9, P10, P11, P12, P13, P14, P15, P16)

Participants also prepared by soaking or wetting the tool with water or warm water.

"First soak the toothbrush with warm water before use" (P2)

"I teach my child to insert the toothbrush into the water and then rub" (P15)

Theme 7: Methods of oral care in children with cancer

The participants in the study revealed that performing oral hygiene in children was required of the participants as parents. The results of this study revealed methods such as coaxing, reminding the child, and asking someone else to brush my children's teeth.

"Coax until the child wants. Let's open your mouth, but, yes" (P1, P7, P10, P13, P16)

"Daily reminder to scrub the teeth" (P3, P4, P5, P9)

"Yes, we do not have, when I cannot do it I ask her father to do that" (P4, P5, P10)

The results of this study showed that participants had a way of performing oral hygiene. They revealed that brushing teeth in children should not be too rough and polish the entire surface of the teeth from various directions.

"Rubbed gently use a soft bristle to brush " (P3, P5, P9, P11, P15)

"I think brushing teeth forward; continue to side, up at the bottom, so normally" (P3, P4, P6, P8, P9, P10)

Additionally, participants revealed the use of different types of water to rinse the mouth, like ordinary water (water in the bathroom), drinking water, warm water or brine.

"Mouthwash use ordinary water" (P3, P4, P7, P8, P9, P11, P12)

"Use of drinking water for mouthwash" (P10, P13, P16).

IV. DISCUSSION

Theme 1. Perceived barriers to performing oral care

Barriers included children's refusal, manifested by crying when parents did oral hygiene. The children's refusal to brush their teeth regularly can act as a barrier for parents in oral hygiene [13]. Physical conditions such as tooth rocking and ulcers, as well as a convenient oral mucosal bleeding, are also parental barriers to performing oral hygiene in children with cancer. The hospital environment was a barrier for parents too. Hospitalization is a threatening experience for children because the stressors encountered can cause feelings of anxiety, fear and stress for children and parents [17][18][19]. The protocol of cancer treatment often requires children to bed rest, so that oral hygiene cannot be done effectively. Hospital rules or routines, medical procedures undertaken such as bed rest, IVs and others are extremely disturbing for children's freedom and independence[20]. This prevents the parents from doing oral hygiene for their children because they feel uncomfortable or hindered.

Feelings of anxiety and fear of the children's condition create pressure on the parents so oral hygiene is hampered because they are worried. Parents felt high anxiety when the child was first treated in the hospital and lacked emotional and social support from the family [21]. Parents' role is very important, but it is not easy because they also experience the psychosocial impact of cancer from the time the child is diagnosed until they are undergoing treatment programs [22]. The anxiety and fear felt by the participants will impact parents' habits regarding oral hygiene.

Theme 2. Sources of parents' experience in performing oral care

Health education was obtained by parents from health professionals. Health education about standard oral hygiene and oral care is a major component in reducing the risk of oral mucositis [23]. Health education in the form of direct counseling to participants will add information about oral hygiene in children so that participants will follow the example of experience which can change their behavior with oral hygiene.

Health education sources were in form of video cartoons or advertisements, television, and YouTube showing parents how to perform oral hygiene. Visual media and communication media are easy to understand [24]. Another study conducted in Turkey showed that planned oral hygiene education using media lectures, demonstrations, and written forms can affect the degree of oral mucositis and pain in the mouth of cancerous children [23]. It can affect participants' attitude to performing oral hygiene in children with cancer. Participants will have the behaviors and habits in oral hygiene in children with cancer from what is gained from the experience of each parent.

Theme 3. Support for parents in performing oral care

Support from the environment means everything will be easier increasing confidence [25]. Suggestions and support are useful because success depends on the efforts undertaken rather than the inborn talents [26]. Instrumental support through interaction with the environment has emotional or behavioral effects to solve the problem and provide greater confidence and competence [27]. Participants will be motivated to make oral hygiene more effective in children with cancer. They were confident in their ability to care for and maintain oral hygiene in children with cancer, and they kept trying to do the best they can.

Theme 4. Benefits of oral hygiene

The perceived impacts felt by parents were a healthier mouth, no toothache, not blackened, and not perforated teeth. The oral cavity is considered healthy when the teeth are not only neat and orderly, but also free of oro-facial pain of chronic cancer, oral lesions, or disorder involving the teeth and mouth [28]. Oral care is very helpful and has a good impact on the condition of the teeth and mouth, especially in childhood cancer which requires more care to prevent and overcome the problems caused by the side effects of treatment.

Dental conditions had a better impact on the participants themselves: which was the worry about the condition of children's teeth and mouth. The parents' reaction toward childhood diseases is influenced by the seriousness of the threat to their children [21]. When children experience changes in conditions, becoming increasingly better, then parents will worry less.

Theme 5. Parental confidence in performing oral care

The results of this study showed that participants perform oral hygiene in children because of their belief and a desire for the children's condition to be improved or cured. Confidence makes the action more effective [16]. Parents act as caregivers, educators, child boosters and supervisors in maintaining oral health by performing oral hygiene [14]. The belief is held to encourage performing oral hygiene in childhood cancer. Parents are needed to improve oral hygiene habits in childhood cancer.

Theme 6. Parental preparation to perform oral care

Participants revealed that some of the tools they used included a toothbrush, toothpaste for children, silicon toothbrushes, and gauze, coarse washcloth or soft jersey fabric. Brushing the teeth using a soft toothbrush or electric toothbrush at least twice a day was shown to significantly reduce the risk of bleeding and infection of the gingiva. A toothpaste that is not too tangy prevents the irritation of the mucous [29]. Parents also prepared tools for oral hygiene with the children's toothbrush moistened before use by using clean water or warm water. A soft bristle brush will not hurt the child's mouth mucosa and warm water reduces the development of bacterial colonies [30].

Theme 7. Methods of oral care in children cancer

The parents' methods are coaxing, reminding, forcing the children, and asking for help from other family members close to the child. Children need their parents in hygiene and oral health because of a lack of knowledge and capabilities [13]. The parents' behavior reminds children to brush their teeth, thereby affecting the condition of children's teeth [31]. Children will usually disobey their parents, so it takes decisive parents to teach discipline to perform oral hygiene in childhood cancer.

Participants said that brushing teeth in cancer children should not be too hard, just rub gently with a soft-bristle toothbrush. A soft toothbrush and warm water are recommended for children with cancer [29]. The use of a soft bristle brush and gently rubbing will not hurt the oral mucosa. Parents said that they used various kinds of water to rinse the child's mouth, such as ordinary water, drinking water, saltwater, and warm water. Oral hygiene can be done with a variety of water, but most importantly the water used has to be clean, as used by the participants in this study. Based on other studies, the use of saltwater for oral hygiene can prevent the formation of dental plaque [32]. Participants used salt water as an option for oral hygiene in children cancer, so the formation of dental plaque in children of cancer could be prevented.

V. CONCLUSION

The perceived barriers experienced by parents come from external and internal factors. External barriers originate from the condition of the child during hospitalization as related to the equipment installed, for example, an IV line, oxygen mask, etc. Internal barriers are strongly associated with concerns about the possibility of bleeding if the child is given oral care. Health education about oral hygiene can provide an understanding of procedures and appropriate information on oral care methods for children suffering from cancer.

CONFLICT OF INTEREST

The authors declare there is no potential conflict of interest.

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