

Quality of Life of Caregiver for Children with Blood Cancer

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Abstract— *Having a child who has blood cancer is certainly not easy for a mother, especially a mother who become the primary caregiver for a child. This certainly can have an impact on the quality of life of a mother. The purpose of this study was to look at the picture of quality of life in mothers of early adulthood (20-40 years). This research is qualitative research using purposive sampling technique and involves four participants (M, A, I, and E). The data collection process was carried out by in-depth interviews from February 2019 to May 2019. The results showed that being a caregiver for a child with blood cancer affected the quality of life of a mother that seen from six dimensions including decreased physical health, decreased mental health, increased social health, spiritual health also getting stronger, changes in daily life, and decreased financial health. To become a better caregiver, mothers should care for their own physical health, they can do some exercise around the house. They have to care about their mental health too, join a support group with people who have a children with cancer too so they can share from heart to heart.*

Keywords: *quality of life, caregiver, mother of children with blood cancer*

I. INTRODUCTION

Cancer is a serious illness. Data from WHO in 2015 showed that 8,8 million people in the world died because of cancer [1]. Cancer affects not only adults but also children. The most common cancer in children is leukemia or blood cancer [2]. Leukemia is a cancer of the blood formation organs, including spinal cord, spleen, and lymph nodes [3]. Children with leukemia need an intensive care both in the hospital and

at home. The parents as the closest person to the children have to support and care for the children, especially mothers who become the primary caregiver for children. Caregiving from mothers to children is important because there is a bonding between two of them that has been formed since their child was born [4]. The presence of a mother can make a child feel safe and speed up the healing process [5].

A mother's life who became a caregiver for a child with blood cancer is not easy, especially when they entering early adulthood's development of life. Early adulthood is a stage of life between 20 and 40 years, characterized with build their career, married, build their family [6]. Early adulthood mothers who become a caregiver have to work, take care their husband and child, and caregiving their other child who is sick. Some of the caregivers told they had a little time for family and friends because they had responsibility to be a caregiver [7]. Research showed that being a caregiver can affect a person's psychological health such as burden that can lead to stress [8] and decreased physical health [9].

All of the impacts of being caregiver can affect early adulthood mother's quality of life. Quality of life is happiness, life satisfaction, well-being, self-actualization, freedom from what is desired, objective function, physical, mental, and social welfare, not only free from disease [10]. Quality of life's of caregiver is defined from six dimensions, physical health; mental health; social health; spiritual health; daily lives; and financial health [11]. Physical health's dimension explains aspects that related with physical health like sleep, fatigue, others symptom, and general health. Mental health's dimension explains about cognition, negative emotions, and positive emotions. Spiritual health dimension explains about making sense of patient's conditions, making sense of caregiver role, and self-transformation. Social

health's dimension explains about social support, family relationships worsen, and family relationships, and reduced social contact. Daily life's dimension explains about daily life constrains, daily life adjustments, daily life strains, and work and career disruptions. Financial health's dimension explains about current financial burden, future financial worries, and financial constraints [11].

II. RESEARCH METHOD

A. *Participants and Design*

The participants of this qualitative study were four mothers who become a caregiver for child with blood cancer. We recruited caregivers from cancer foundation in Jakarta, social media, and television from February to May 2019. The criteria for the caregivers are mother who has a child with blood cancer, aged 20 years until 40 years, with their educational background is graduating from junior high school or above, willing to give informed consent and to be voice recorded. Data collection is done by interview.

B. *Interview Guide*

An interview guide based on caregiver Quality of Life domains [11] was used and questions were asked to describe mothers's physical health, mental health, spiritual health, social health, daily life, and financial health [11]. Interviews were voice recorded and transcribed into verbatim. Interviews were ranged from 40-60 minutes.

III. RESULTS AND DISCUSSION

A. *Research Results*

Physical Health

Physical Health is defined as one's good condition in the body, free from disease and other parts [10]. This dimension comprised four themes: 'sleep', 'fatigue', 'others symptom', and 'general health'. Sleep refers to how the quality of sleep the individual has and the problems associated with sleep quality such as sleep disorders. Sleep disorders experienced by an individual can cause a decrease in quality of life [12]. Three of the participants had no problem with sleep, while the other one (E) had problem with sleep.

Fatigue describes the energy and fatigue felt by

individuals while they're doing their activities. Four mothers felt fatigue because they had a lot of activities like cooking, clean the house, taking care of their child, etc. Fatigue made their general health decreased, also four participants reported others symptom. 'M' reported that she often feels sore on her body and feels dizzy. 'A' and 'I' reported that when she really tired, she feels dizzy. 'E' reported that she had cholesterol and hypertension.

Mental Health

Mental health contains aspects related to a person's mental condition that affect his quality of life. This dimension comprised three themes: 'cognition', 'negative emotions', and 'positive emotions'. Cognition want to see how the memory and concentration of individuals on their daily activities. Four participants reported that they had lower memory and concentration because they had a lot of activities that they had to do. Four participants also felt negative emotions like anxiety about their child condition, sadness, helplessness when their child was in pain, strain, and guilt about what happened to their child. Two of the participants, 'M' and 'E' felt angry about their life. Four participants also felt positive emotions like feeling blessed and hoped their child will recover soon.

Spiritual Health

Spiritual health is defined as individual's ability to find meaning and purpose in life [11]. Spiritual health also want to see one's relationship with God after their child is sick. There are three aspects in this domain: 'making sense of patient's condition', 'making sense of caregiver role', and 'self-transformation'. 'making sense of patient's condition' refers to how caregiver understand the patient's diagnosis [11]. Four participants understood about their child's diagnosis, they could explain about the diagnosis clearly. 'making sense of caregiver role' refers to caregiver understanding to their role [11]. Four participants understood their role like taking care their child, supporting their child, and accompany their child for treatment in the hospital. 'self-transformation' refers to caregiver transformation to more positive [11]. 'M' told that when she became caregiver for her child, she became realizes what the love's meaning and pray more often. 'A' became more religious and used gamis syar'i as her clothes. 'I' became more religious and pray more often. 'E' became more open with others and pray more often.

Social Health

Social health want to see how individual's interaction with others. There are four aspects in this dimension: 'social support', 'family relationship worsen', 'family relationship improve', and 'reduced social contact'. 'social support' refers to support that one's get from family or friends. Four participants got their support from their family and especially from other moms that had a child with cancer too. All of the participants felt that support from other moms that had a child with cancer were really helpful for them. 'family relationship worsen' refers to conflict that one's had with their family [11]. Two of the participants, 'I' and 'E' got worsen relationships with their family. 'I' and 'E' had a conflict with their husband's family because of financial problem.

'family relationship improve' refers to increased bonding with family members [11]. One of participants, 'M' felt no improve on her relationships with her family because she had no time to gather with her other family. 'A', 'I', and 'E' felt their relationships with their family got improve, their family members care more about their child's condition. 'reduced social contact' refers to less time one's spent with friends [11]. 'M' and 'A' told that they had no time to catch up with their old friends because they focused to take care their child. 'I' and 'E' felt they had a lot of friends in the hospital that can support each others.

Daily life

This domain has four aspects: 'daily life constrains', 'daily life adjusments', 'daily life strains', and 'work and career disruptions'. 'daily life constrains' refers to one's has no time for recreational activites or not able to do what he/she want to do. 'M' had no time for recreational activity because she used her free time to get a rest. 'A' wanted to do some sewing course, but because of her child's condition, she couldn't do it. 'I' wanted to go back to her hometown, but her child's condition made her had to postpone it. 'E' really wanted to get a job, but no one will take care her child while she is working. 'daily life adjusments' refers to one's ability to adapt with their life. One of the participants felt a little bit hard to adapt in the hospital while three of other participants got no problem. 'daily life strains' want to see one's life problems while being a caregiver. Two of the

participants, 'M' and 'I' felt trouble with their daily life. 'M' felt trouble when her child couldn't control her emotions. 'I' felt trouble because she had to take her child to hospital and saw her child in pain because of medication. 'work and career disruptions' refers to disruption in work or career like stop work or cannot find work. 'M' had to stop work because her child is sick. 'A' could not do a sewing course. 'I' cancelled her plans to open restaurant. 'E' had to close her shop because her child is sick.

Financial Health

This domain has three aspects: 'current financial burden', 'future financial worries', and 'financial constrains'. All of the four participants felt current financial burden because of their child's medication is expensive. Also, 'E' had no job and her husband is dead. Four participants worried about their future financial. They all already sold their property like house, gold, estate, etc. all of the participants also had a financial constrains that made them had to scrimp.

TABLE I. DEMOGRAPHIC OF PARTICIPANTS

<i>Participant's</i>	<i>Participant 1</i>	<i>Participant 2</i>	<i>Participant 3</i>	<i>Participant 4</i>
Name	M	A	I	E
Participant's age	30 tahun	27 tahun	29 tahun	38 tahun
Number of	2	1	2	2
The order of children who have	First child	First child	Second child	Second child
Age of child that suffering from cancer	6 years old	6 years old	4 years old	8 years old
Type of cancer	Blood cancer type ALL	Blood cancer type ALL	Blood cancer type ALL	Blood cancer type ALL
Participant's job	Housewife	Housewife	Housewife	Housewife
Husband's job	Driver	unemployment	Chef	(already dead)

B. Discussion

Based on the results of the analysis, in general each participant reported that there was a decrease in some dimension in their quality of life. The researchers found

that all mothers who become caregivers of child with cancer had decreased physical health. The four participants experienced fatigue due to the many tasks that must be done as a caregiver. In addition, after undergoing chemotherapy treatment, their children became more fussy and difficult to sleep, which also caused the four participant couldn't sleep and had to look after their children. Lack of sleep can cause them to get tired and experience a decrease in health. Fatigue is felt to be one of the factors that makes the four participants experienced a decrease in physical health.

Being a caregiver has a close relationship with health problems because of the many tasks and work done by a caregiver. The number of tasks and activities that must be done can cause a caregiver to experience fatigue and health problems such as headaches, high blood pressure, hypertension, and other chronic diseases [13]. This happened to all four participants. Decreased physical health can affect a person's quality of life [10].

In the mental health dimension, all participants have experienced aspects of negative emotions as well as positive emotions. This shows that being a caregiver can have a positive and negative effect on their lives. The four participant felt negative emotions such as anxiety, stress, anger, guilt, and feeling helpless. The participants were worried about the health condition of his child and were worried about the effects of the chemotherapy treatment that was felt. One of the participant even showed symptoms of depression because her husband had died. Being single mother turns out to be at a higher risk of developing a depression disorder because it has greater stress exposure such as poverty or negative life events [14]. The theory is in accordance with what happened to one participant, since her husband has died, she experienced difficulties in the economy because she did not work. In addition, the death of her husband and child who had cancer also became a negative life event that could cause the participant to experience depression.

Negative emotional aspects felt by the participants are in line with the theory which states that being a cancer caregiver can make caregivers feel sad, anxious, angry, and depressed [15]. In

addition, the theory also mentions that a caregiver usually experiences feelings of fear about the effects of treatment that a loved one undergoes [15], this is consistent with what happened to the participant. The four participants also felt surrender and said that if they could choose, it would be better if she felt the pain compared having to see their children in pain. The bonding of a mother and child is indeed very strong and has been formed since the child was born [16], which makes a mother willing to sacrifice for her child.

The four participants also felt positive emotions in caring for their children, one of which was feeling valued. This is consistent with the results of research that show that being a caregiver can make someone feel valued for having carried out their role [17]. The results also show that positive emotions and negative emotions are closely related to one's life satisfaction [18]. Life satisfaction is closely related to quality of life [10].

On the dimensions of spiritual health, the four participants have an increase in their spiritual life with God and that helps them to always be strong. Moreover, because Indonesia itself is ranked third with a country that has a high religious level [19], this is related with what happened to the participant that is more submissive and surrendered to God. In addition, the improvement of the participant's spirituality life is also in line with the theory that being a caregiver can increase their spiritual beliefs [20]. Spirituality does not only discuss religiosity but also how one finds meaning and purpose in their lives [21]. The four participants also felt a change in themselves towards a better direction. This is related with the results of research which states that being a caregiver can affect one's self-development[22].

The health condition of the person being treated is sometimes unpredictable, it can make a caregiver feel stressed because of the uncertainty. Spirituality helps a caregiver deal with the stress of caring for a patient or loved one with a serious illness [23]. Apart from that good religious life can also help an individual to control their stress such as having a better coping mechanism, more social support, and strength in personal values [21]. This was felt by the four participants that spirituality helped them to face their lives. The results of the study even show that someone who has a high spiritual level will have a higher life expectancy [24].

Based on the Kübler-Ross theory, there are five stages of a person passing through a grief, the first being rejection, anger, bargaining, depression, and acceptance [25]. Participants

experienced rejection, anger, bargaining, until depression when they found out their child had cancer, but over time, the participant began to be able to accept the condition of his child and was at the acceptance stage so that he could organize his life again. This proves what happened to the participant is related with the theory. The results of the study also showed that individual spirituality plays an important role in the grieving process experienced by someone [26].

On the dimensions of social health the four participants get support from family, neighbors, and also mothers who also have cancer children. Support from the people closest to the participant is felt to be very helpful for the participant to go through difficult times, especially in Indonesia which has a strong family culture and a high level of collectivity [27]. This is in line with the theory that informal social support can help mothers as caregiver children with cancer reduce their stress. Informal support itself in the form of suggestions, instructions, and direction that can help caregivers face personal and situational demands [28]. Social support is very important, even research shows that social support in the form of information and emotional support can improve the quality of life of a cancer patient [29].

Some participant felt a change in daily activities since becoming a child caregiver, they could not travel much, recreation and could not do the activities they wanted to do and withdraw from old friendships. In addition, the participant also feels a change in his work and career. All participants stopped working and did not continue the career they dreamed of, even though at the age of the early adult participant they would focus on their future such as continuing their education to a higher level or working. Work is important for an early adult woman, especially for those who do not want to work as housewives [30].

Research also shows that being a caregiver can disrupt work such as less energy while working, work less productively or efficiently, reduce working hours, disrupt work activities, reduce work responsibilities, get out of work [13]. This is consistent with what happens to participants who stop working. Changes in lifestyle and social activities are felt more by a female caregiver and this can affect individual well-being [13]. This is contrary to what the participant sees about their lifestyle and can affect individual well-being. Individual well-being is closely related to the quality of

life.

Expensive medical expenses are a burden on caregivers. The four participants considered that their income could not meet the needs that they had to fulfill, especially in terms of the cost of child medicines that must be redeemed, although some participants received some help from several foundations, but their financial conditions remained difficult. One participant experienced worse financial conditions because her husband had died so she did not have a steady income. Low income affecting the possibility of the individual experiencing depression [31]. This is in accordance with what happened to the participant because she experienced several symptoms of depression. In addition, a difficult economic level can cause a woman to have a higher level of negative emotions compared to men [31]. This is in accordance with what happened to the four participants, they experienced negative emotions.

For the further study, the researches propose to use mix method and use a questionnaires so the result can be more comprehensive.

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