

ORIGINAL RESEARCH

QUALITY OF LIFE OF FAMILY CAREGIVERS OF CHILDREN WITH LEUKEMIA: A DESCRIPTIVE QUANTITATIVE STUDY

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Abstract

Background: Treatment of children with cancer can affect daily lives of family caregivers. This can disrupt roles in social life, limit daily activities, disrupt health and physical and emotional balance as well as causing economic problems and creating poor quality of life.

Objective: To describe the quality of life of family caregivers of children with leukemia based on characteristics of parents and children.

Methods: This was a descriptive quantitative study. The population was all parents as the primary caregivers who had children aged 0-15 years diagnosed with leukemia in pediatric wards of Provincial General Hospital of Dr. Hasan Sadikin Bandung, Indonesia. Thirty-four respondents participated in this study selected using a total sampling. The quality of life of family caregivers was measured using the quality of life family version standard questionnaire, and the children's severity of leukemia was identified by the severity of illness scale standard questionnaire. Data were analyzed using frequency distribution, mean, and standard deviation.

Results: The study results showed that family caregivers had poor quality of life (58.8%), with the worst sub-dimension including physical and psychological health conditions (55.9%), followed by social conditions (52.9%), and spiritual health conditions (50.0%). The majority of family caregivers who had the poorer quality of life were at the older age, male, having a primary education level, caring for their children for less than 12 months with severe leukemia, and having an average monthly income of fewer than 1.5 million rupiahs.

Conclusion: Poor quality of life was identified among family caregivers of children with leukemia. Therefore, it is suggested for nurses to provide nursing care holistically not only for the children but also the families to increase their quality of life.

KEYWORDS

caregivers; quality of life; parents; leukemia; child; Indonesia

BACKGROUND

Cancer is a term for disease in which cells divide abnormally without control and can attack the surrounding tissue ([National Cancer Institute, 2009](#)). Cancer can strike all ages, including children, and it is considered the second leading cause of death in children aged five to 14 years ([Ministry of Health of the Republic of Indonesia, 2015](#)). The Indonesian Child Cancer Foundation also said that the prevalence of cancer in children increases by 7% each year ([Yayasan Onkologi Anak Indonesia, 2017](#)). The incidence of childhood cancer in Indonesia is around 2-4%. Every year, there are 11,000 cases of cancer in children and 10% of them cause death ([Widodo & Amanda, 2018](#)). Based on data from [Provincial General Hospital of Dr. Hasan Sadikin Bandung \(2017\)](#), chemotherapy in cancer patients was the most frequent case in the Department of Pediatrics and Child Health, as many as 1,412 patients. While in January to October 2017, there were 952 cases of cancer in children aged 0-18 years in Provincial General Hospital Dr. Hasan Sadikin Bandung.

[The Indonesian Pediatrician Association \(2017\)](#) revealed that 3/4 of cases of malignancy in children in Indonesia occurred due to leukemia. In addition, global data showed that nearly 300,000 cases of childhood cancer from 2001-2010 showed that leukemia was the most experienced type of childhood cancer ([Saputra, 2017](#)). According to data from [Provincial General Hospital of Dr. Hasan Sadikin Bandung \(2017\)](#), there was 328 children who had leukemia in the last ten months of 2017.

Cancer diagnosis and treatment have a big impact not only for patients but also for families, and they affect every aspect of family life ([Duci & Tahsini, 2012](#)). Complex treatment protocols, including chemotherapy, intra-spinal drug injection, radiotherapy, and surgery lead to anxiety in the children and parents. The emotional reactions of parents to chronic illnesses experienced by their children have the potential to cause symptoms of post-traumatic stress and affect their

quality of life (Tsai et al., 2013). Caring for cancer patients can interfere with the quality of life of parents as informal primary caregivers.

Quality of life is defined as individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns (WHOQOL Group, 1995). Quality of life consists of four sub-dimensions, specifically physical health conditions, psychological health, social health, and spiritual health conditions (Kudubes, Bektas, & Ugur, 2014). Quality of life in older people can be influenced by several factors, such as characteristics of parents including age, gender, level of education, culture, length of care given to the child, amount of income, and as characteristics of children including severity of disease (Song, Nam, Park, Shin, & Ku, 2017; Turkoglu & Kilic, 2012).

A research conducted in Sri Lanka showed that nearly 50% of parents of children with leukemia had a low quality of life (Pathirana, Goonawardena, & Wijesiriwardane, 2015). According to Mancini et al. (2011), parents experienced various kinds of physical problems as a consequence of their roles in caring for children with cancer. The physical health problems frequently complained by parents were very severe fatigue, lack of time to rest, weight loss, and loss of appetite, which could be influenced by parental characteristics such as age, gender, education level, culture, income, and length of care to the children (Hacalioglu, Özer, Erdem, & Erci, 2010; Kim & Spillers, 2010; Lim et al., 2017; Song et al., 2017).

A previous research conducted in China showed that parents of cancer patients experienced high emotional stress, with 54% of moderate to severe anxiety and 21% of depression. Parents of cancer patients also experienced fatigue, fear, feelings guilty, anxiety, depression, despair, regret, sleep problems, and high social isolation (Song et al., 2017). In addition, parents felt their social relationships were disrupted because they only focused on patients so that their own needs were neglected (Stenberg, Ruland, & Miaskowski, 2010). They most likely focused all their attention on maintaining patient care, managing pain, helping patient mobilization, meeting the patient's daily needs, contacting health workers, and delivering patients to get treatment (Kudubes et al., 2014; Turkoglu & Kilic, 2012). Additionally, they felt guilty about the fact that they were genetically responsible for the disease, and were worried and doubt about the future of their children (Mancini et al., 2011).

However, psychological and social problems in the parents can be influenced by the characteristics of parents and children (Hacalioglu et al., 2010; Kim & Given, 2008; Kong, 2007; Lim et al., 2017; Litzelman, Catrine, Gangnon, & Witt, 2011; Song et al., 2017). Besides, negative experience can be dangerous because it can cause stress and physical health to be deteriorated, disrupted financial problems, sleep disorders, and other psychological problems for the parents of cancer children. These negative experiences can also affect the ability of parents to care for children with cancer (Song et al., 2017). According to Weaver and Flannelly (2004), those who have adequate spiritual conditions can accept the disease that occurs, and try to overcome it in a positive and directed manner.

Parents are the main source of emotional and social support for children with cancer, and they are responsible for how well patients carry out their disease. The level of difficulty experienced by parents when

knowing their child is diagnosed with cancer has an important effect on the child's psychological adjustment (Stenberg et al., 2010). The parents' declining quality of life can influence the quality of care and the quality of life of the patient (Turkoglu & Kilic, 2012). The involvement of parents is very important in the optimal management of cancer patients to ensure treatment compliance and continuity of care. If parents experience sustained fatigue and a decrease in quality of life, this can result in delays in the care that the child must undergo and this can drop the child's health condition off. Therefore, the quality of life of parents must be considered for the good of the parents themselves as an informal primary caregiver as well as patients' health (Mancini et al., 2011).

Research in Indonesia related the quality of life in 33 family members who treated children with leukemia who underwent chemotherapy at Provincial General Hospital of Hasan Sadikin Bandung showed that 54.5% of family members had a good quality of life. It could happen since the family had adapted to the responsibility of care since the child got the disease (Gamayanti, Rakhmawati, Mardhiyah, & Yuyun, 2012). However, the study only examined the quality of life in each dimension without analyzing it based on the characteristics of parents and children although the characteristics of parents and children such as parents' age, sex, education level, income, duration of care given to children, culture, and the severity of illness suffered by children are the factors that can influence quality of life.

The aim of our present study was to identify the quality of life of family caregivers in children with leukemia based on the characteristics of parents and children.

METHODS

Study Design

This study used a descriptive quantitative design.

Participants

The participants in this study were all parents as the primary caregivers and having children aged 0-15 years who were diagnosed with leukemia in inpatient rooms of Kenanga I and II at Provincial General Hospital of Hasan Sadikin Bandung, East Java, Indonesia. Thirty-four participants were selected using a total sampling technique.

Instrument

There were two instruments in this study: 1) The standard questionnaire of quality of life family version developed by Ferrell and Grant (2005) was used to identify the quality of life of parents (Ferrell & Grant, 2005). The questionnaire consists of 37 questions categorized into four sub-dimensions, especially physical health conditions (5 items), psychological health (16 items), social (9 items), and spiritual health conditions (7 items). All questions are measured using an ordinal differential semantic scale, with negative and positive statements with the lowest score of 0 and the highest score of 10. A good quality of life is indicated if the score \geq means value.

The scale has been translated into Indonesian language by a linguist at the Language Center of the Faculty of Cultural Sciences, Universitas Padjadjaran, and back-translated into English by another linguist at the Language Center, Faculty of Cultural Sciences, Universitas

Padjajaran. The accuracy of the translation results was carried out by the other linguists as a translator at the English Language Education Institute (Think English) Bandung. After the translation process, validity content testing was carried out by a lecturer at the Faculty of Nursing at the Universitas Padjadjaran, followed by face validity with ten parents who asked for family caregivers for children with leukemia at Provincial General Hospital of Hasan Sadikin Bandung, Indonesia. The scale had an item content validity index of 0.790, and reliability value using Cronbach Alpha of 0.923.

2) The severity of illness scale questionnaire was used to see the severity of leukemia in children that was developed by [Young-Saleme and Prevatt \(2001\)](#). The scale has an item content validity index of 0.790 and a reliability value using Cronbach Alpha of 0.800. The scale is available in Indonesian language. This questionnaire has been translated into Indonesian by [Nursyamsyah \(2018\)](#). The questionnaire consisted of 6 questions related to the seriousness of the disease using the Likert scale with a value of 1 to 7.

Data Collection

The study was carried out in the inpatient room of Kenanga I and II at Provincial General Hospital of Dr. Hasan Sadikin Bandung. The study was conducted from April to May, 2018. Data were collected by distributing the questionnaires after the respondents have agreed to participate in this study and have signed informed consents. The data collection was done by the researchers and one research assistant, a nurse in the inpatient room of Kenanga I and II at Provincial General Hospital of Dr. Hasan Sadikin Bandung. Briefing prior to data collection was done to ensure that the perception of the researcher and research assistant was the same.

Data Analysis

Data were analyzed using descriptive statistics. As the data were normally distributed, mean and standard deviation were used. The higher the mean value, the higher the quality of life and the severity of leukemia suffered.

Ethical Consideration

The study was ethically approved by the Health Research Ethics Committee of Provincial General Hospital of Dr. Hasan Sadikin Bandung with number LB.4.01/A05/EC/035/11/2018. The study permission was also obtained from the Department of Research and Education of Provincial General Hospital of Dr. Hasan Sadikin Bandung with number LB.02.01/X.2.2.1/6125/2018. Prior to data collection, informed consents were made to all respondents. The objectives and the procedures of the study had been explained, and confidentiality of each respondent was ensured.

RESULTS

Quality of Life of Family Caregiver of Children with Leukemia

Table 1 showed that the average of the quality of life of family caregivers of children with leukemia was 198.12 with a standard deviation of 43.580. The minimum value of quality of life was 116 and the maximum value was 296. Table 2 revealed that overall quality of life of family caregiver of children with leukemia was poor (58.8%).

Table 1 Quality of Life of Family Caregivers of Children with Leukemia (N=34)

| | Mean | Standard Deviation | Minimum-Maximum Value |
|-----------------|--------|--------------------|-----------------------|
| Quality of Life | 198.12 | 43.580 | 116-296 |

Table 2 Category of Quality of Life of Family Caregivers of Children with Leukemia (N=34)

| Quality of Life Category | f | % |
|--------------------------|----|------|
| Good | 14 | 41.2 |
| Poor | 20 | 58.8 |

Table 3 Subdimension of Quality of Life of Family Caregivers of Children with Leukemia (N=34)

| Sub-Dimensions of Quality of Life | Mean | Standard Deviation | Minimum-Maximum Value |
|-----------------------------------|-------|--------------------|-----------------------|
| Physical Health Conditions | 28.79 | 8.559 | 15-46 |
| Psychological Health Conditions | 68.62 | 21.617 | 36-108 |
| Social Conditions | 48.24 | 19.311 | 9-84 |
| Spiritual Health Conditions | 52.47 | 9.699 | 24-70 |

Table 3 showed that the sub-dimension of psychological health conditions had the highest mean value of 68.62 while the sub-dimension which had the lowest mean value was the physical health conditions (28.79). And Table 4 showed that the majority of respondents (55.9%) had the poor quality of life in the sub-dimension of psychological health conditions and physical health conditions. Meanwhile 50.0% of respondents had a good quality of life in the spiritual health conditions sub-dimension. However, the frequency distribution in each sub-dimension of the quality of life had no significant difference.

Table 4 Category of Sub-Dimensions of Quality of Life of Family Caregivers of Children with Leukemia (N=34)

| Sub-Dimensions of Quality of Life | Quality of Life | | | |
|-----------------------------------|-----------------|------|------|------|
| | Good | | Poor | |
| | f | % | f | % |
| Physical Health Conditions | 15 | 44.1 | 19 | 55.9 |
| Psychological Health Conditions | 15 | 44.1 | 19 | 55.9 |
| Social Conditions | 16 | 47.1 | 18 | 52.9 |
| Spiritual Health Conditions | 17 | 50.0 | 17 | 50.0 |

Table 5 showed that younger parents tended to have a better quality of life compared to older parents. In addition, the percentage of male parents (63.6%) who experienced a decreasing quality of life were more than female parents (56.5%). In addition, parents who had a higher level of education and total income tended to have a better quality of life compared to the parents who had a lower education level and amount of income. Also, parents from Java, Sunda, and Sumatera inclined to have poor quality of life. Parents who have cared for their sick children for less than 12 months (59.3%) and their children with more severe disease (66.7%) had a high percentage in the poor quality of life category.

Table 5 Quality of Life of Family Caregivers of Children with Leukemia According to Characteristics of Respondents (N=34)

| Characteristics of Respondents | Quality of Life | | | |
|--|-----------------|-------|----------|-------|
| | Good | | Poor | |
| | <i>f</i> | % | <i>f</i> | % |
| Parent's Age | | | | |
| Late Youth (17-25 years) | 1 | 50.0 | 1 | 50.0 |
| Early Adult (26-35 years) | 6 | 46.2 | 7 | 53.8 |
| Late Adult (36-45 years) | 4 | 33.3 | 8 | 66.7 |
| Early Elderly (46-55 years) | 3 | 50.0 | 3 | 50.0 |
| Late Elderly (56-65 years) | 0 | 0.0 | 1 | 100.0 |
| Parent's Gender | | | | |
| Male | 4 | 36.4 | 7 | 63.6 |
| Female | 10 | 43.5 | 13 | 56.5 |
| Parent's Education Level | | | | |
| Primary School | 2 | 18.2 | 9 | 81.8 |
| Junior high school | 4 | 33.3 | 8 | 66.7 |
| Senior high school | 6 | 75.0 | 2 | 25.0 |
| College | 2 | 66.7 | 1 | 33.3 |
| The Duration of Giving Care to Children | | | | |
| <12 months | 11 | 40.7 | 16 | 59.3 |
| >12 months | 3 | 42.9 | 4 | 57.1 |
| Severity of Leukemia Suffered by Children | | | | |
| Mild | 8 | 50.0 | 8 | 50.0 |
| Severe | 6 | 33.3 | 12 | 66.7 |
| Total Parent Income per Month | | | | |
| <1.5 million | 6 | 28.6 | 15 | 71.4 |
| 1.5-2.5 million | 2 | 66.7 | 1 | 33.3 |
| 2.5-3.5 million | 3 | 50.0 | 3 | 50.0 |
| >3.5 million | 3 | 75.0 | 1 | 25.0 |
| Parent's Culture | | | | |
| Java | 2 | 25.0 | 6 | 75.0 |
| Sunda | 11 | 47.8 | 12 | 52.2 |
| Sumatera | 0 | 0.0 | 2 | 100.0 |
| Betawi | 1 | 100.0 | 0 | 0.0 |

DISCUSSION

The quality of life of family caregivers of children with leukemia at the Provincial General Hospital of Dr. Hasan Sadikin Bandung was poor which against the results of a previous study conducted by [Gamayanti et al. \(2012\)](#) at the same hospital, which revealed that there was a good quality of life of family caregivers of children with leukemia. This distinct result might be due to the use of different questionnaires. The previous questionnaire on the physical dimension only examined one facet and rest, while in the spiritual dimension only examined the relationship with God. In our study, the questionnaires are more comprehensive covering all facets of each dimension, thus describing the results more thoroughly as well. Although the results of this study are different from the research conducted by [Gamayanti et al. \(2012\)](#), the results of this study are in line with the research by [Lim et al. \(2017\)](#) and [Song et al. \(2017\)](#) which revealed that parents who took care for children with cancer are likely having poor quality of life.

Good or poor quality of life of the parents however can be influenced by the characteristics of the children and the parents themselves. The results of our study showed that older people tended to have poor quality of life. These results are consistent with a study conducted by [Song et al. \(2017\)](#), mentioned that older caregivers experienced higher emotional stress and a lower quality of life. According to [Rohmah and](#)

[Bariyah \(2015\)](#), this can occur because, at a later age, a person will experience changes in physical, cognitive, or social life, so that it can worsen their quality of life, which in turn affects the quality of care for their children. The results of our study also showed that the majority of older people experienced poor quality of life in the sub-dimension of physical health conditions. The results of this study somehow are consistent with the research conducted by [Kim and Spillers \(2010\)](#) found that younger caregivers had better physical health compared to the older ones. This may be related to the ageing process that occurs in each individual.

[Pangkahila \(2007\)](#) revealed that each individual has three stages of the ageing process. The first stage is called the subclinical stage when a person is in the age range of 25-35 years. At this stage, most of the hormones in the body begin to decline, besides that the formation of free radicals can damage body cells, but at this stage, the decrease in hormones and body cells damage is not too visible. The second one is the transition stage when individuals are in the age range of 35-45 years. The hormone levels decrease to 25% and free radicals begin to damage the genetics so that it can lead to several diseases, such as arthritis, reduced memory, infectious diseases, and various other diseases. The last stage is the clinical stage when individuals reach the age of 45 years and above. At this stage, the decrease in hormone levels continues.

There is also an alleviation in body function and the immune system so that individuals are more susceptible to disease.

Furthermore, the results showed that 50% of parents, in the range of 17-25 years old (late adolescents), experienced psychological health conditions have poor quality of life. According to the social role theory, younger parents may experience greater pressure because they should adjust to their new roles as parents. Also, more than 50% of parents, aged 36-65 years, experienced the psychological health conditions have poor quality of life. [Rohmah and Bariyah \(2015\)](#) stated that at a later age, individuals might experience psychosocial changes. The results of this study also revealed that most parents, in the late adult age category (36-45 years), experienced the social conditions have poor quality of life. According to [Santrock \(2013\)](#), at this time individuals usually experience an increase in social activity. However, parents who take care for children with leukemia would feel their social relationships are disrupted because they only focus on the needs of patients, so they have poor quality of life ([Stenberg et al., 2010](#)).

Based on the gender, male and older people (63.6%), especially in the social and spiritual sub-dimensions, have poor quality of life. According to [Lim et al. \(2017\)](#), this can happen because men have a role as the backbone of the family, so they find it difficult to divide their time between working and taking care of their sick children. It is not easy for a father to play a dual role as a breadwinner and helping his wife in caring for a sick child ([Khoury, Huijjer, & Doumit, 2013](#)). As a result, many patriarchs often cannot participate in social activities, eventually, have to stop working as a consequence of caring for their sick children, and this can increase emotional stress ([Wadhwa et al., 2013](#)). [Pathirana et al. \(2015\)](#) and [Lau et al. \(2014\)](#) also mentioned that many parents have to stop working because they have to take care of their children and continue to meet the cost of care, which could increase the burden and reduce the quality of life.

Based on the results of this study, we also found that the parents who had a good quality of life in the sub-dimension of spiritual health conditions mostly female as much as 52.2%. It is in line with a statement of [Kim and Spillers \(2010\)](#), women have greater spiritual values. In this case, what is meant by spirituality is not only a relationship with God, but also a relationship with themselves, others, and also nature. [Alvin Rich \(2012\)](#) revealed that the differences in the level of spirituality in women and men could due to factors such as emotional, psychological, and judgment of the surrounding environment. Men and women have different ways of expressing their spirituality. Women tend to be more sensitive to emotional relationships, more involved in feelings, and more understanding of others. Whereas men further limit their personal feelings. [Durik et al. \(2006\)](#) mentioned that women and men could feel the same emotions but women tend to be more able to express their feelings such as shame, happiness, sadness, affection, guilt, and sympathy compared to men. [Stark \(2002\)](#) also stated that the difference in spirituality levels might also be related to physiological factors, while men tend to be more impatient than women because men have more testosterone than women. In addition, [Stark \(2002\)](#) also revealed that the judgment in the society could affect one's spirituality. People see the perpetrators of violence and crime tend to be men, so society considers women have a higher level of spirituality and religiosity than men. This assumption made women meet the society's assumption to be more religious.

Most female parents who experienced the sub-dimension of physical health conditions had a have poor quality of life (65.2%). According to [Hagedoorn, Sanderman, Bolks, Tuinstra, and Coyne \(2008\)](#), it could happen because women have the main role as administrators of children, households, and husbands. When one family member is sick, women usually become the main nurse in taking care of the sick family member, so that the burden borne by women can increase and this may have a negative impact on their physical health. In addition, female parents also tend to have poor psychological conditions (56.5%). According to [Hagedoorn et al. \(2008\)](#), women experience higher psychological pressure because, in addition to being in charge of caring for their children, they also have to take care of their households and husbands. Furthermore, women are also more sensitive to emotional relationships, more involved in feelings, and more understanding of others. So that it tends to make women dissolved in sadness related to the conditions experienced by their children at this time, and that can reduce their psychological well-being ([Alvin Rich, 2012](#)).

Based on the level of education, the results revealed that parents who had the poor quality of life were mostly primary school graduates (81.8%). These results are different from the previous study conducted by [Song et al. \(2017\)](#) and [Litzelman et al. \(2011\)](#) stated that parents with higher education had poorer quality of life because they were actively involved in the medical decision-making process so that it could increase stress and reduce their quality of life. However, these results related the quality of family caregiver's quality of life of children with leukemia carried out in the Provincial General Hospital of Dr. Hasan Sadikin Bandung are in line with the results of research conducted in the Netherlands by [Van den Tweel et al. \(2008\)](#). The results of their research showed that low levels of education in children's caregiver with anemia are associated with high pain scores and low motor function experienced by the caregivers. It happened because parents with low education had a perception of poor health so that it could lower the quality of life.

The results of this study also showed that family caregivers who had the poor quality of life mostly got low income, the average monthly income was less than 1.5 million rupiahs (71.4%). This is consistent with a statement from [Dumont et al. \(2006\)](#), parents with economic difficulties experience increased parenting burdens and decreased quality of life. The financial burden can cause parents to experience stress so that it can reduce their quality of life ([Santo, Gaiva, Espinosa, Barbosa, & Belasco, 2011](#)). Moreover, the treatment cost for leukemia is quite expensive so that it can increase the family's financial burden ([Klassen et al., 2011](#); [Song et al., 2017](#)). [Hacalioglu et al. \(2010\)](#) also stated that low income might cause poor quality of care, while high income might significantly affect life satisfaction.

The findings also showed that parents who had cared for their children affected by leukemia for less than 12 months had the majority of poor quality of life (59.3%) compared to parents who had cared for their children for more than 12 months (57.1%). These results are in line with the research conducted by [Klassen et al. \(2011\)](#), which showed that parents who cared for their children less than 12 months experienced a worse quality of life because in the first 12 months children still needed a higher intensity of care. Besides, [Lim et al. \(2017\)](#) also mentioned that caregivers had a higher burden of care at the time of the initial diagnosis. [Lau et al. \(2014\)](#) in his research on family life experiences in the first year of caring for a child with ALL found that 46% of parents

stopped working thereby reducing their income and creating a family financial burden. Moreover, the difference in the quality of life between parents who cared for their children for less than 12 months and those who care for their children more than 12 months can also occur because of parents' psychosocial health increases over time. In the early stages of diagnosis, parents experience shock, rejection, disappointment, depression, and anxiety about the diagnosis of leukemia that occurs in their child. In the early stages of diagnosis, parents also cannot adjust to the conditions experienced by their children (Pai et al., 2007). Previous research has also shown that considerable stress is experienced by parents and children in the first year of children diagnosed with leukemia (Hedström, Ljungman, & von Essen, 2005). Tsai et al. (2013) also found that stress levels experienced by parents and children began to decline after undergoing treatment in the first six months. Increasing psychosocial conditions in parents can also occur because of parents' experience and confidence in caring for their children is also increasing over time (Leow, Chan, & Chan, 2014).

In our study, the parents also tended to have poor quality of life in caring for children with severe leukemia. These results are consistent with the research conducted by Kim and Spillers (2010), which stated that caregivers who treated cancer patients with more advanced stages had a heavier burden and lower quality of life compared to those who treated early-stage cancer patients. According to Lim et al. (2017), it can occur because in cancer patients with a more advanced stage, caregivers experience more pressure due to having to prepare themselves to face patient deaths and provide palliative care, where palliative care planning and issues to deal with death are one sensitive issue which can increase stress. This study also found that mostly parents who cared for their children with severe leukemia had poor physical conditions (61.1%). The poor physical conditions experienced occur due to the increasing burden of the treatment. In worse conditions, patients need more intensive care, so that the time needed to treat patients every day becomes longer so that the fatigue felt by parents increases (Leow et al., 2014).

CONCLUSION

It is concluded that the family caregivers in children with leukemia had poor quality of life including in all sub-dimensions of quality of life. Therefore, it is suggested for nurses to provide nursing care holistically not only for the children but also the families. Health care institutions also should make a family support group, specifically for family caregivers to support each other and share their experience in treating leukemia.

DECLARATION OF CONFLICTING INTEREST

The authors declare no conflicts of interest.

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AUTHORS CONTRIBUTION

IN conceptualized and designed the study. SH conducted the literature search and reviewed data. DPH performed the data collection. IN, SH, DPH drafted the manuscript. All authors conceived of the presented idea, provided critical

feedback, and analyzed the research as well as discussed, the results and contributed to the final manuscript. All authors contributed to the writing of the manuscript. All authors read, edited, and approved the final manuscript.

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