

ORIGINAL RESEARCH

THE CORRELATION BETWEEN FAMILY FUNCTIONING AND QUALITY OF LIFE OF CAREGIVER OF CHILDREN WITH LEUKEMIA

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Abstract

Background: Quality of life of caregiver of children with leukemia is important because it can affect the quality of care provided and can affect the health of children and the caregiver themselves. One of the factors that influence the caregiver's quality of life is the family functioning. However, a few number of research on the correlation of family functioning in the caregiver's situation.

Objective: The aim of the study was to analyze the correlation between family functioning and the caregiver's quality of life of children with leukemia.

Methods: This study used a Quality of Life Family Version questionnaire and a Family Assessment Device questionnaire. The populations in this study were all parents (father or mother) who were the primary caregiver of children with leukemia aged 0-15 years and were being treated at a referral hospital in West Java, Indonesia. Thirty-two respondents were determined by a total sampling technique. The data analysis used frequency distribution and chi-square.

Results: The results showed that the family functioning and quality of life of the caregiver had the same results, 50% good and 50% poor. Correlation test in this study showed a negative value with p value > 0.05 (0.480), which indicated that there was no correlation between family functioning and the quality of life of the caregiver.

Conclusion: The correlation between family functioning and caregiver's quality of life was not significant. This is likely due to the variable family functioning and the caregiver's quality of life having balanced results. The results of this study need to be followed up by providing nursing care holistically not only to children, but also to families, especially who are directly involved in child care.

KEYWORDS

children; family functioning; leukemia; parents; quality of life

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INTRODUCTION

Cancer does not only occur in adults, but also in children. According to World health Organization ([WHO, 2017](https://www.who.int/)), the incidence of cancer in children increases every year. The number reaches 110-130 cases per one million children. In Indonesia, every year the Indonesian Child Protection Commission records 4,100 new cancer cases occur in children ([Indonesian Child Protection Commission, 2017](https://www.kemkes.go.id/)). According to Indonesian Child Oncology Foundation, types of cancer that

frequently occur in children in Indonesia are leukemia and retinoblastoma ([Indonesian Childhood Cancer Foundation, 2017](https://www.ichcf.org/)). Leukemia that often occurs in children is acute lymphoblastic leukemia (ALL). A study found that leukemia is a type of cancer that occurs in children under 15 years, around 30-40%. In addition, other data revealed that the incidence of leukemia in Indonesia is around 2.5-4.0 per 100,000 children with an estimated 2000-3200 new cases of LLA each year.

Based on the data from one referral hospital in West Java, the number of children suffering from leukemia cancer in the first ten months of 2017 was 328 children. Therefore, this study focuses on pediatric patients with leukemia.

In the treatment process, parents always accompany children. In this case, parents have a role as caregivers. Caregiver is someone who is fully responsible and directly involved in the patient care process. Caregiver is a person who is fully responsible and directly involved in patient care, such as fulfilling the basic needs and treatment of patients. There are two types of caregivers, namely formal caregivers and informal caregivers. Formal caregivers are people who provide professional, trained, paid care, and are part of a service system such as hospitals, health centers, psychiatrists or other professionals. While informal caregivers are people who provide care but not experts or professionals, do not get paid, and live together or not with patients. Informal caregiver consists of parents, children, spouse, friends, relatives, or neighbors ([Duci & Tahsini, 2012](#)).

The care provided by both father and mother as an informal primary caregiver is not only limited to fulfilling the needs of daily activities, but more complex than that. Caregiver has a heavy responsibility in taking care of patients such as caring for patients, financing for treatment and providing emotional support ([Hudson et al., 2010](#)). In addition, the family has a role as an advocate, medical and technical counselor. Parents learn to identify and see the side effects of treatment received by their children. The dilemma of parents involved in child care is when parents provide care that is often painful and frightening for children, but on the other hand parents want to entertain, protect and keep children from suffering and pain ([Jones, 2012](#)).

In the care process, the caregiver's responsibilities are carried out over a long period of time which can be a burden for the caregiver. The study revealed that the consequences of prolonged care in children with cancer caused a negative impact on the caregiver, which caused stress and decreased quality of life ([Litzelman, Catrine, Gangnon, & Witt, 2011](#)). Quality of life is a condition where an individual is in a state of prosperity. Quality of life is a subjective matter where everyone has a different quality of life. The caregiver's quality of life in cancer patients can change due to a new role in caring for cancer patients, lack of social support, problems with work and lack of time to gather with family ([Duci & Tahsini, 2012](#)).

Quality of life of a person could be influenced by several factors. In general, factors that can affect a person's quality of life are individual characteristics and environmental characteristics ([Wilson & Cleary, 1995](#)). Based on literature review ([Son et al., 2012](#)), the factors that can affect the caregiver's quality of life with cancer children include sociodemographic factors (age, gender, education, and culture), cancer that the child has (type of cancer, severity of cancer and duration of treatment), condition of the caregiver (psychological, health, family functioning, and social support). McMaster's family functioning model theory proposed by Epstein ([Epstein, Baldwin, & Bishop, 1983](#)) stated the process

of the family system as the core, and assumed that the basic function of family is to provide appropriate environmental conditions for family members to develop on the physical, psychological, social and other aspects ([Dai & Wang, 2015](#)). Family functioning is a complex concept covering affective, structural, control, cognitive, and external relations dimensions. Examples of family functioning include harmonious relationships, the involvement of family members (affective dimensions), the division of responsibilities and roles between family members (structural dimensions), the maintenance of a safe family condition (control dimensions), the decision making and problem solving in deliberation (cognitive dimensions), and maintaining a positive relationship with relatives (external relations dimension) ([H.-S. Kim & Kim, 2008](#)).

According to previous study ([Son et al., 2012](#)), family functioning is an important factor in the quality of life of the caregiver. Caregiver with a good family functioning has a better quality of life in all domains, except burden. Another study ([Rodríguez-Sánchez et al., 2011](#)) states that the quality of caregiver's life is observed from 4 dimensions, namely dimensions of social support, general satisfaction, physical and mental health and lack of free time. Of the 4 dimensions examined in this study, only physical and mental health dimensions have an effect on family functioning. From the results of this study, family functioning shows that physical health and mental caregiver are seen from the satisfaction received from their families, discussion with their families, being able to feel family affection, satisfied with the time the family spent with them and making family decisions.

Good family functioning or functional family is where all family members participate, contribute and work together on an equal basis and with enthusiasm for collective welfare. Sometimes some family members take care of their dependents, but more often the burden of care is carried out by one person: the main caregiver. In the care process, this significantly affects the caregiver in physical, mental, social and economic aspects. The care process carried out by the caregiver can cause burdens such as excessive tasks and usually change the dynamic of family functioning ([Rodríguez-Sánchez et al., 2011](#)).

According to literature ([Yagc-Küpelı, Akyüz, Küpelı, & Büyükpamukçu, 2012](#)), if the caregiver's quality of life decreases, it may cause a direct negative impact on the quality of life of the child. If parents are stressed about their child's condition, it will affect the child's clinical condition, treatment outcomes and physical suffering. A study also mentioned that if there is an improvement in the caregiver's quality of life and there is a decrease in the stress level of the caregiver, this can improve the quality of life of children with cancer ([Tsai et al., 2013](#)). The importance of family functioning in cancer childcare requires nurses to provide nursing care not only to children, but also provide nursing care to families. Family has an important role in nursing because families provide important resources to provide health services for themselves and others in the family ([Tinkham, Voorhies, & McCarthy, 1984](#)). Providing care refers to the family as a patient from a community nurse with a focus primarily on family needs and resolution ([Ali, 2010](#)).

METHODS

Study design

The type of research used was a correlational research, which is a study or analysis of the relationship between two variables in a situation or group of subjects. In this study, the researcher aimed to examine the correlation between family functioning and the quality of life of caregivers who have children with leukemia. The research approach used in this study was cross sectional where the researcher only did one-time data collection from each respondent (Arikunto, 2013).

Sample

The populations in this study were all parents who had a role as primary caregivers of children with leukemia aged 0-15 and were being treated in a referral hospital in West Java, Indonesia. The inclusion criteria in this study were all parents from children aged 0-15 years who suffered from leukemia and were willing to be respondents in this study. The exclusion criteria in this study were parents who were not willing to be respondents. The time of research began in May until June 2018. In this study, 32 respondents were determined by total sampling technique.

Instrument

The instrument used in this study consisted of 2 instruments, Family Assessment Device (FAD) and Quality of Life Family Version. The Family Device Assessment Questionnaire consists of questions categorized into seven sub-variables, namely solving problems, communication, family roles, affective responses, affective involvement, control behavior, and general functioning (Epstein et al., 1983). This instrument was modified by the researcher by adding six statements regarding the family care function. The FAD instrument consisted of 66 statements, divided into 35 negative statements and 31 positive statements measured using a Likert scale. Each negative statement has the lowest score of 1 and the highest score of 4, while each positive statement has the lowest score of 4 and the highest score of 1. It is said to have good family functioning if the score of family functioning \geq mean value. The Quality of Life Family Version instrument consisted of 37 questions divided into 21 negative

statements and 16 positive statements categorized into four sub-variables, namely physical health conditions, psychological health conditions, social conditions, and spiritual health conditions (Ferrell, 2005). This instrument is measured using the Osgood scale. There are negative and positive statements with the lowest score 0 and the highest score 10. Some question items have an inverse score, for example when the respondent circles the number "4" in the answer, the score given is 6 ($10 - 4 = 6$). It is said to have good quality of life if the score \geq mean value. The instrument has been back translated, the method was used to check the accuracy of a translation. In this method, the questionnaire was translated into Indonesian by a linguist at the Language Center of the Faculty of Culture Sciences, Universitas Padjadjaran and translated back into English by another linguist. Then the accuracy of the translation results were carried out by translator team in English education institutions.

Ethical consideration

This research was carried out by upholding ethical principles namely autonomy, confidentiality and justice. This study was approved by the health research ethics committee in Dr. RSUP Hasan Sadikin Bandung with an approval number LB.04.01/A05/EC/115/1V/2018.

Data analysis

Univariate data in this study used descriptive analysis, namely the frequency distribution. Whereas for bivariate analysis was used chi-square correlation test.

RESULTS

Univariate Analysis

In **Table 1** it is shown that half of the respondents had a good quality of life (50%), while **Table 2** showed that most respondents (56.3%) had a poor quality of life in the subdimension of psychological health conditions. Meanwhile 53.1% of respondents had a good quality of life in the subdimension of physical health, social health and spiritual health conditions.

Table 1 Frequency Distribution of Caregiver's Quality of Life in Children with Leukemia (N=32)

Quality of Life Category	f	%
Good	16	50
Poor	16	50

Table 2 Sub-Dimensional Frequency Distribution of Caregiver's Quality of Life in Children with Leukemia (N=32)

Sub-dimensions of Quality of Life	Caregiver's Quality of Life			
	Good		Poor	
	f	%	f	%
Physical health conditions	17	53.1	15	46.9
Psychological health conditions	14	43.8	18	56.3
Social conditions	17	53.1	15	46.9
Spiritual health conditions	17	53.1	15	46.9

Table 3 Frequency Distribution of Caregiver's Quality of Life in Children with Leukemia based on Respondent Characteristics (N=32)

Respondent Characteristics	Caregiver's Quality of Life			
	Good		Poor	
	<i>f</i>	%	<i>f</i>	%
Age				
Late Adolescent (17-25 years)	2	28.6	5	71.4
Early Adult (26-35 years)	8	61.5	5	38.5
Late Adult (36-45 years)	5	45.5	6	54.5
Early Elderly (46-55 years)	1	100.0	0	0.0
Sex				
Male	5	62.5	3	37.5
Female	11	45.8	13	54.2
Education				
Primary School	2	28.6	5	71.4
Junior High School	5	35.7	9	64.3
High School	7	87.5	1	12.5
College	2	66.7	1	33.3
Duration of Giving Care to Children				
<12 months	12	54.5	10	45.5
>12 months	4	40.0	6	60.0
Income per month				
<1.5 million	9	42.9	12	57.1
1.5-2.5 million	4	66.7	2	33.3
2.5-3.5 million	2	50.0	2	50.0
>3.5 million	0	0.0	1	100.0
Ethnic group				
Javanese	2	25.0	6	75.0
Sundanese	14	58.5	10	41.7

Table 3 showed that younger parents tend to have a better quality of life compared to elderly parents. In addition, the percentage of parents who were female (54.2%) experienced a decrease in quality of life more than parents who were male (37.5%). However, when observed from the level of education and the amount of income, parents who had higher levels of

education and higher income tend to have a better quality of life. When observed from a cultural background, Javanese parents (75.0%) tend to have poor quality of life than Sundanese parents (41.7%). In addition, parents who had treated their sick children for more than 12 months (60.0%) had a poor quality of life.

Table 4 Frequency Distribution of Family Functioning in Children with Leukemia (N=32)

Family Function Category	<i>f</i>	%
Good	16	50
Poor	16	50

In **Table 4** it is shown that half of the respondents had a good family functioning (50%), while **Table 5** shows that family functioning items in children with leukemia had a poor category in behavioral control items (81.3%). Meanwhile the item of

family functioning that was in a good category is problem solving item and function in general (40.6%).

Table 5 Frequency Distribution of Family Functioning Items in Children with Leukemia (N=32)

No	Item	Good		Poor	
		<i>f</i>	%	<i>f</i>	%
1.	Problem solving	13	40.6	19	59.4
2.	Communication	10	31.3	22	68.8
3.	Role	9	28.1	23	71.4
4.	Affective Response	12	37.5	20	62.5
5.	Affective Involvement	10	31.3	22	68.8
6.	Behavioral Control	6	18.8	26	81.3
7.	Function in general	13	40.6	19	59.4
8.	Health Care Functioning	11	34.4	21	65.6

Table 6 Frequency Distribution of Family Functioning in Children with Leukemia based on Characteristics of Respondents (N=32)

Respondent Characteristic	Family Function			
	Good		Poor	
	<i>f</i>	%	<i>f</i>	%
Age				
Late Adolescent (17-25 years)	3	42.9	4	57.1
Early Adult (26-35 years)	3	23.1	10	76.9
Late Adult (36-45 years)	10	90.0	1	9.1
Early Elderly (46-55 years)	0	0.0	1	100.0
Sex				
Male	4	50.0	4	50.0
Female	12	50.0	12	50.0
Education				
Primary School	3	42.9	4	57.1
Junior High School	5	35.7	9	64.3
High School	6	75.0	2	25.0
College	2	66.7	1	33.3
Duration of Giving Care to Children				
<12 months	12	54.5	10	45.5
>12 months	4	40.0	6	60.0
Income per month				
<1.5 million	10	47.6	11	52.4
1.5-2.5 million	3	50.0	3	50.0
2.5-3.5 million	2	50.0	2	50.0
>3.5 million	1	100.0	0	0.0
Ethnic group				
Javanese	14	58.3	10	41.7
Sundanese	2	25.0	6	75.0

Table 6 revealed that younger parents tend to have poor family functioning compared to elderly parents. In addition, considering from the level of education and the amount of income, parents who had higher levels of education and higher income tend to have good family functioning compared to parents who had lower levels of education and income. From a cultural background, Javanese parents tend to have poor family functioning (75.0%) than Sundanese parents (41.7%). In addition, 60.0% parents who have treated their sick children for more than 12 months had poor family functioning.

Bivariate analysis

Bivariate analysis in this study determines the correlation of family functioning with the caregiver's quality of life in children with leukemia. **Table 7** showed that p value of the correlation is 0.480, greater than 0.05, which means the correlation between family functioning and caregiver's quality of life in children with leukemia is insignificant.

Table 7 Correlation of Family Functioning with Quality of Life Caregiver in Children with Leukemia (N=32)

Family Function	Caregiver's Quality of Life				p value
	Poor		Good		
	<i>f</i>	%	<i>f</i>	%	
Poor	7	43.8	9	56.3	0.480
Good	9	56.3	7	43.8	

DISCUSSIONS

Quality of life of caregiver of children with leukemia

The quality of life of caregiver of children with leukemia in this study showed that as many as 50% of parents have a poor quality of life and as many as 50% of parents have a good quality of life. Previous research ([Gamayanti, Rakhmawati, Mardhiyah, & Yuyun, 2012](#)) at RSUP Dr. Hasan Sadikin Bandung showed that the caregiver's quality of life in children with leukemia was in a good category, but there was also result of another studies ([Lim et al., 2017](#); [Yu et al., 2017](#)) which stated that parents who cared for children with cancer had a

poor quality of life. Based on each sub-dimension of quality of life (see **Table 2**), the majority of parents had a poor quality of life in the sub-dimension of psychological health conditions (56.3%). While caring for their children, parents experience decreased concentration and memory; parents also experience feelings of oppressed, stress, and difficulty in caring for their sick children. These feelings may arise because of the additional burden on parents in the form of financial burden or responsibility burden ([Hacialioglu, Özer, Erdem, & Erci, 2010](#)). Medical and treatment costs including drugs and diagnostic tests for serious diseases such as cancer are quite high, so that obviously can enhance the financial burden of parents ([Yousuf](#)

[Zafar, 2015](#)). While the burden of responsibility may arise because parents must provide care to their sick children for a long period of time ([Stenberg, Ruland, & Miaskowski, 2010](#)). The additional responsibility felt by parents is that besides having to take care of their sick children, they also have to take care of household affairs, their spouse and other children.

Parents experience anxiety, apprehension, and fear of the diagnosis of leukemia that occurs in their children. They are afraid of the prognosis of the disease that afflicts their children making them feel anxious at all times ([Khoury, Huijjer, & Doumit, 2013](#)). The apprehensive feeling of being abandoned and sad when they see their children experience difficult conditions is naturally felt, but if it is excessive, it can have a bad impact on psychological health. Parents may not concern to the quality of care given to their child because it is dissolved in the perceived sadness, and this will have an impact on the patient's quality of life ([Park et al., 2013](#)).

From the characteristics of respondents (**Table 3**), the results of the study showed that younger parents tend to have a poor quality of life. According to previous study ([Y. Kim & Spillers, 2010](#)), at a younger age they have a high level of stress because of the new role as a caregiver. Poor quality of life also appears more in parents with female gender (54.2%). Women who care for family members with cancer have a lower quality of life than men who care for family members with cancer ([Y. Kim & Given, 2008](#)).

Characteristics of respondents at the education level showed that parents who had a poor quality of life were mostly from primary school (71.4%). According to study ([van den Tweel et al., 2008](#)) that the low level of education of caregivers of children with anemia is associated with low motor function and high pain scores experienced by the caregiver. This occurs because parents with low level of education have a poor perception of health, so that it may decrease the quality of life. In addition, the results of the study also showed that parents who have a poor quality of life are mostly in low-income parents, with an average monthly income less than 1.5 million rupiah (57.1%). As expressed by Dumont *et al.* ([Dumont et al., 2006](#)), that parents with economic difficulties experience an increased burden of care and a decrease in quality of life. The existence of a financial burden can cause parents to experience stress so that it can reduce their quality of life ([Kitrungrote & Cohen, 2006](#); [Santo, Gaíva, Espinosa, Barbosa, & Belasco, 2011](#)).

Considered from a cultural background, Javanese parents from have a poor quality of life. Researchers assumed the culture of parents in this study as parents with Asian cultural backgrounds. According to previous study ([Yu et al., 2017](#)), parents who care for leukemia children with Asian cultural backgrounds have a poor quality of life compared to parents with Western cultural backgrounds. This can happen because in Asian countries, family members play an important role in treating patients in the hospital. They also do many tasks that if in Western countries, the task is carried out by nurses.

Family functioning in children with leukemia

Family functioning in children with leukemia in this study showed that as many as 50% of parents have a poor family function and as many as 50% of parents have a good quality of life (see **Table 4**). In the study conducted by Martin *et al.* ([Martin et al., 2012](#)), it showed that parents who care for children with leukemia have good family functioning. Whereas another study ([Alderfer, Navsaria, & Kazak, 2009](#)) stated that parents who care for children with leukemia have poor family functioning. Based on sub-dimension of family functioning, parents have poor family functioning in the dimension of behavior control (81.3%). This is in accordance with previous research ([Watson et al., 2006](#)) which stated that parents, namely father or mother, have poor behavioral control when a child has cancer. Poor behavioral control in parent will make children suffering from cancer have external problems. Parents' behavior in this matter can be demonstrated by providing support to their children during the treatment process.

The results of this study also showed that parents who had treated their children for more than 12 months had the majority of poor family functioning (60%) compared to parents who have cared for their child less than 12 months (57.1%). According to ([Sloper, 2000](#)), 18 months after diagnosis, it was found that the level of distress of most parents was not reduced and some parents showed an increased level of distress related to family relationship and repeated hospital care. Families' ability to overcome multiple sources of stress and uncertainty associated with the diagnosis and treatment of their child's cancer will probably affect the quality of life of children. From the perspective of the family system, what happens to one family member influences other members. In turn, how families respond to difficulties affecting children's responses and functioning, in a sequence of circular effects ([Hosoda, 2014](#)).

In this study, from the amount of parents' income per month, parents whose income <1.5 million per month has poor family functioning (52.4%). According to previous study ([Panganiban-Corales & Medina, 2011](#)), low income families will have difficulties in fulfilling their daily needs. When their child is treated for a long time, the medical expenses will increase so they sometimes cannot afford the medical expenses. Meanwhile, according to Young *et al.* (2005) ([Yun et al., 2005](#)), families who have low income more often use their savings money for medical expenses because they have financial problems or do not have health insurance to pay for medical expenses that have been incurred. According to Klassen *et al.* ([Klassen et al., 2011](#)), low income families will have an economic burden. This economic burden will have a long impact on their family life. Parents need a supportive and flexible work environment during their child's care and need to learn about how to access various financial and other resources available to help with treatment expenses.

Correlation of family function and quality of life of caregiver of children with leukemia

The results showed that the p value of correlation was 0.480, which means that the correlation between variables of family functioning and caregiver's quality of life was not significant.

The results of data analysis on the caregiver's quality of life and family functioning showed half good and half poor. The results of this study prove that it is not entirely a state of good quality of life due to good family functioning but can be due to other supporting factors.

The results of this study were different from the results of the previous study (Rodríguez-Sánchez et al., 2011) which stated that family functioning had a correlation with the quality of life of the caregiver. This is because in their study, the number of respondents was 153 people and the questionnaire used was Family APGAR and Ruiz-Baca QoL test. Their study stated that the dimensions of quality of life that have a correlation with family functioning are only the dimensions of physical health and the dimensions of psychological health. A study conducted by Yu et al. (Yu et al., 2017) also showed that there is a correlation between family functioning and caregiver's quality of life. This is because in this study the number of respondents was 309 people and the questionnaires used were Family APGAR and WHOQOL-BREF. The study stated that the quality of life of the caregiver and family functioning both have poor category results. In the study also mentioned that the dimensions of quality of life that have a correlation with family functioning are psychological dimensions, social dimensions and environmental dimensions. Another study (Son et al., 2012) also showed a correlation between family functioning and caregiver's quality of life. In this study, the number of respondents was 100 people and the questionnaires used were Family APGAR and CQOLC. The study mentioned that the dimensions of quality of life that have a relationship with family functioning are dimensions of disturbance, dimensions of positive adaptation and dimensions of financial problems.

The results of this study indicate that there is no correlation between family functioning and caregiver's quality of life, so that there is a possibility that there are still other factors that have more influence on the quality of life of the caregiver. According to study (Son et al., 2012), there are factors that can affect the quality of life of the caregiver with a child with cancer. These factors include sociodemographic factors (age, gender, education, and culture), cancer that children have (type of cancer, severity of cancer and duration of treatment), condition of the caregiver (psychological, health and social support). Limitations in this study are the number of respondents. However, referring to the results of this study, it is very important for nurses and other health workers to provide holistic nursing care not only for pediatric patients with cancer but also for their families, so that not only the patient's quality of life is good but also the quality of life of their caregiver.

CONCLUSION

Family functioning in children with leukemia and caregiver's quality of life in children with leukemia shows similar results, namely 50% good and 50% bad. These results indicate that there are still parents who have poor quality of life and poor family functioning. Based on these results, it indicates that family functioning is not correlated to the quality of life of the

caregiver in children with leukemia with the results of $p > 0.05$. This is obtained because the variables of family functioning and quality of life of the caregiver have balanced results. The results of this study need to be followed up by providing nursing care holistically not only to children, but also to families, especially parents who are directly involved in child care. Nursing care for families need to be a concern so that good quality of life and family functioning are maintained well and also to improve the quality of life and family functioning that are still in the poor category.

Declaration of Conflicting Interests

The authors declare no conflicts of interest.

Authorship Contribution

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. AF performed the data collection

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