

Age and disease duration as factors affecting the Quality of Life of caregivers of Thalassemia patients in Indonesia

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Abstract

Thalassemia is a chronic disease that disrupts caregivers' Quality of Life (QoL), causing physical, emotional, social, and financial burdens. The aim of this study was to determine the relationship between several risk factors affecting the QoL of caregivers of thalassemia patients. A comparative analytic cross-sectional study was carried out through direct telephone interviews from 97 subjects, who met the inclusion criteria, to assess the risk factors and the QoL using the TranQoL questionnaire. The subject response rate was 70% and the QoL with the lowest proportion was found in the physical health dimension. The correlation of the risk factors between child age and disease duration in the emotional dimension was significant, as well as the relationship between income level and the QoL in the family dimension. Therefore, QoL intervention is required as a form of prevention and early detection of parental psychosocial problems through telemedicine counseling in pandemic situations.

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1. Introduction

Thalassemia is a recessive inherited blood disease caused by a genetic mutation of the globin chain, resulting in abnormal hemoglobin production (Raza, Farooqi, Mubeen, Shoaib, & Jabeen, 2016). It is characterized by microcytic hypochromic anemia and clinical manifestations of varying severity. Furthermore, thalassemia's genetic defects cause a decrease or absence of mRNA in one or more globin chains, or the formation of functionally defective messenger RNA. It results in a decrease or total suppression of hemoglobin polypeptide synthesis. More than 100 different mutations have been found worldwide, resulting in a unique thalassemia phenotype based on local geographic area (Ayu NP, 2015; Rodiani dan Anggoro, 2017). The prevalence of this disease was initially found in the Mediterranean Sea region. However, due to inter-ethnic marriage and migration of people in search of work and a better life, it is presently almost found worldwide (Wulandari, 2018). Indonesia is one of the countries with the highest prevalence of thalassemia in Asia (Alyumnah, Ghozali, & Dalimoenthe, 2016). According to the data from YTI-POPTI (Indonesian Thalassemia Foundation – Association of Parents of Thalassemia Patients), there has been an increase in the prevalence of thalassemia in Indonesia, which has continued from 2012 (4,896 cases) to 2018 (8,761 cases) with a slight decrease registered in July 2017 in the West Java Province by 40.2% or around 3,264 incidences (P2PTM Kemenkes RI, 2019).

Parents are the closest family as caregivers for thalassemia patients and they face many challenges in providing a high-quality service to their children. Patients with severe thalassemia undergo routine blood transfusions since they experience daily anemia (Marnis, Indriati, & Nauli, 2018). Anemia occurs due to ineffective hemolysis processes, caused by an imbalance in the synthesis of globin chains, which causes insolubility and damage to the red blood cells and their precursors (Ali, Sabih, Jehan, Anwar, & Javed, 2012; Kumar, Abbas, & Aster, 2012). Routine transfusions provide a special burden because those infected with severe thalassemia experience iron accumulation, causing complications to various organs, such as the liver, spleen, heart, kidney, and endocrine system (Marnis *et al.*, 2018). Since the COVID-19 (Coronavirus Disease 2019) pandemic, all society levels have restricted access to basic services, such as kindergartens, schools, and routine medical care. The partial closure, or reduction of inpatient and outpatient services, has been restricted to all cases with the only exception of emergency cases. Some hospitals have been unable to

admit newly hospitalized patients due to the risk of infection. The lack of access to basic services due to the stigma against COVID-19 patients makes people reluctant to visit the health facilities. This condition is dangerous for thalassemia patients in terms of therapy continuity (Fegert, Vitiello, Plener, & Clemens, 2020).

The cost of disease treatment, the socioeconomic status, the public's lack of knowledge and understanding of thalassemia as well as the perceptions of genetic inheritance, have increased the demand for an excessive role on caregivers and feelings of mutual blame for the same (Apsari, 2016; Falentina & Dariyo, 2016; Rujito, Dwi Lestari, Santosa, & Hapsari, 2017; Adnan Abo Jeesh, El-hadi Ahmad Yousif, & Al-Balal Al-Haboub, 2018). Previous research has shown that the burden of thalassemia patients most heavily affects caregivers' quality of life in the school and career dimension. This is related to the limited time for parents to work because they have to take care of their children, which, in turn, has an impact on the caregivers' financial burden (Paramore, Levine, Bagshaw, Ouyang, Kudlac, & Larkin, 2021). This financial burden is exacerbated by the impact of the limiting of social activities, due to the COVID-19 pandemic, which has caused economic losses, especially for developing countries, such as Indonesia (Hadiwardoyo, 2020). During the COVID-19 pandemic, there was a reorganization of everyday life. All family members were expected to cope with the stress of quarantine and social distancing. Caregivers were under increasing pressure to work from home, alongside children attending school from their residence. Meanwhile, caregivers' social resources, including the help of grandparents and the wider family, were restricted for the danger of transmitting the virus (Fegert *et al.*, 2020). This burden made them prone to stress problems related to lack of social support, financial difficulties, poor service effectiveness, as well as worries concerning the child's future (Rakhmilla, Iskandar, Susanah, Rohmawaty, & Effendi, 2020).

The Quality of life (QoL) is defined by the World Health Organization as individuals' perception 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 (Hussenoeder, Jentzsch, Matschinger, Hinz, Kilian, Riedel-Heller *et al.*, 2021). In addition, caregivers' quality of life in taking care of thalassemia children is influenced by the personal and environmental circumstances (specifically: age, disease duration, mother's age, number of family members, education, and income level; Piran, Khademi, Tayari, & Mansouri, 2017). Indicators of quality of life differ for each country due to differences in sociocultural and socioeconomic factors,

ethnicity, and other factors (Biswas, Naskar, Basu, Dasgupta, Basu, & Paul, 2020). Presently, there is limited research on the dimensions of the caregiver's quality of life compared to the therapy to prevent complications in thalassemia patients. The description of patients' quality of life by caregivers for children with developmental disabilities has been carried out in Indonesia without analyzing the risk factors, using non-specific measuring tools (Dewi & Mu'in, 2015). The purpose of this study was to assess the relationship between several risk factors affecting the quality of life of caregivers of thalassemia patients with a measuring tool developed according to the target population, namely the TranQoL (transfusion-dependent QoL) questionnaire (Klaassen, Alibhai, Allen, Moreau, Pulcini, Forgie *et al.*, 2013). This tool is known to be more effective in examining the caregivers' actual situation and the factors influencing it (Poengoet, Sungkar, & Pandji, 2017).

2. Aims and hypothesis

The aim of this study was to determine the relationship between the risk factors affecting the quality of life of caregivers of thalassemia patients and to answer to the following questions: (a) is there a correlation between the age of thalassemia patients and the life quality of the caregiver? (b) is there a correlation between the mother's age and the life quality of the caregiver? (c) is there a correlation between the number of family members and the life quality of the caregiver? (d) is there a correlation between disease duration and the life quality of the caregiver? (e) Is there a relationship between education level and the life quality of the caregiver? (f) is there a relationship between income level and the life quality of the caregiver?

3. Method

3.1. Sample

This study collected 137 cell phone numbers, which were registered as belonging to mothers of children with thalassemia and who attended the Thalassemia Polyclinic, Dr. Hasan Sadikin, Bandung (Indonesia) on a regular basis for routine transfusions of their children. Subsequently, invitations to participate in the study were distributed through the WhatsApp group during the July - August 2020 period.

3.2. Procedure applied

This study was conducted using a comparative analytic method with a cross-sectional approach. The subjects were confirmed to be mothers of thalassemia children without hearing disorders and were willing to participate in the study after obtaining informed consent as an inclusion criteria in this study. The exclusion criteria was limited to cases in which the respondent could not be contacted by telephone. The subjects were contacted by telephone between 8 am-5 pm, and, in case the respondent was unreachable for the first time, a second telephone call was attempted. During the interview, via cell phone, subjects were explained the study procedure and phone calls were recorded with the respondent's consent; the respondent was asked to fill in the informed consent form as well as other questionnaires. The latter included questions about general characteristics, selected risk factors (mother's and patient's age, disease duration, number of family members, education and income level), and questions regarding the TranQoL questionnaire (Klaassen *et al.*, 2013). This study has already obtained the ethical approval from the Research Ethics Committee of the Faculty of Medicine, Padjadjaran University (Bandung, Indonesia) with number 591 / UN6.KEP / EC / 2020.

3.3. Research instrument used

The TranQoL questionnaire (Klaassen *et al.*, 2013) is a research instrument, which was developed by Dr. Robert Klaassen in 2013. It was distributed by the Mapi Research Trust to evaluate the quality of life of people with thalassemia, especially those depending on blood transfusions. The questionnaire used consists of 38 items in which there are several dimensions, specifically physical health (2 items), emotional health (23 items), sexual activity (1 items), family (7 items), school, and career (5 items). The TranQoL scoring system is weighed on each valid questionnaire with a scale of 0 to 4 by reverse scale for the positive items response: 0 = never, 1 = almost never, 2 = sometimes, 3 = often, 4 = always. The calculation of the total score for each quality of life dimension is obtained in the form of a percentage using the excel formula, namely: $IF(\# \text{ of truly missing} < 25\% \text{ of total number of questions (i.e. } < 8 \text{ for proxy/child or } < 10 \text{ for parent and adult), } 100 * (1 - ((\text{sum of valid responses}) / ((\text{total } \# \text{ of valid responses}) * 4))), \text{ ""})$. Scores can range from 0 to 100 percent for each dimension. This instrument divides the quality of life into good and bad

categories. Therefore, when the QoL is good, it has a score above the average dimension.

The TranQoL in this study was adapted by Dr. Robert Klaassen's validity and reliability tests (Klaassen, Barrowman, Merelles-Pulcini, Vichinsky, Sweeters, Kirby-Allen *et al.*, 2014), which were carried out by Poengoet and collaborators (Poengoet *et al.*, 2017) on families with thalassemia patients at the Dr. Hasan Sadikin Bandung Hospital in 2017. The test of validity ($r > r$ table) and reliability ($\alpha = .92$) have been reported to be quite good in previous studies in the target population (Poengoet *et al.*, 2017).

4. Data analysis

The data analysis used statistical software (Microsoft Excel 2019 and IBM SPSS version 22.0). The risk factors for mother's and patient's age, disease duration, and number of family members were tested by Spearman analysis. Moreover, the risk factors for education and income level were subjected to the Mann-Whitney assessment. Results were considered to be statistically significant when the p -value $< .05$.

5. Results

A total of 137 telephone numbers was collected as belonging to mothers of children with thalassemia. Of these, 97 respondents accepted the invitation and agreed to be interviewed by telephone while the remaining 40 were classified as ineligible (1 died, 13 were unwilling to participate in the research and 26 were unable to be contacted). The response rate (i.e. the number of respondents that were successfully interviewed in relation to the total sample that met the requirements) was around 70%.

As shown in Table 1, most of the mothers ($n = 60$; 62%) had an age ranging between 18 and 40 years old while most of the thalassemia children ($n = 50$; 52%) were aged between 5 and 11 years old. On average, the disease duration was more than eight years and the number of nuclear family members was ideal (4 people). In terms of education level, most participants presented a Senior High School diploma or higher form of education (i.e. college) and nearly 60% of the subjects have an average level of income above the minimum wage.

Table 1 – *Characteristics of the research participants (n = 97)*

Characteristics	<i>M; SD</i>	<i>n; %</i>
Age of mothers in years	37.72; 7.95	
18 – 40		60; 61.90
41 – 60		36; 37.10
> 60		1; 1
Age of children with thalassemia in years	9.77; 4.23	
< 5		9; 9.30
5 – 11		50; 51.50
> 11		38; 39.20
Disease duration in months	102.06; 53.46	
< 12		3; 3.10
12 – 60		21; 21.60
> 60		73; 75.30
Number of family members	4.09; .92	
Education level		
High school or equivalent		88; 90.70
College		9; 9.30
Income level		
< UMP		40; 41.20
≥ UMP		57; 58.80

< UMP = Under Provincial Minimum Wage (< Rp1.810.350); ≥ UMP = Above Provincial Minimum Wage (≥ Rp1.850.350).

The bivariate analysis results are presented in Tables 2 and 3, describing the relationship between the risk factors (i.e. age of mothers and children, disease duration, number of family members, education, and income level) and the 5 QoL dimensions (i.e. physical health, emotional, sexual, families, education and career) for caregivers of thalassemia patients. As shown by the Spearman rank correlation, the age of thalassemia patients as well as the disease duration were significantly correlated to the emotional dimension of the caregiver's quality of life ($p = .02$ and $.03$, respectively; refer to Tab. 2 for more details). This meant that the younger the child's age and the longer the disease duration, the more the parents felt an emotional burden, affecting their quality of life. Other variables, such as the age of the mothers and the number of family members, did not show a significant correlation ($p \geq .05$) with the QoL dimensions of the caregivers.

Table 2 - Correlation of age of mothers and children, disease duration and number of family members on the Quality of Life (QoL) dimensions for caregivers of thalassemia patients

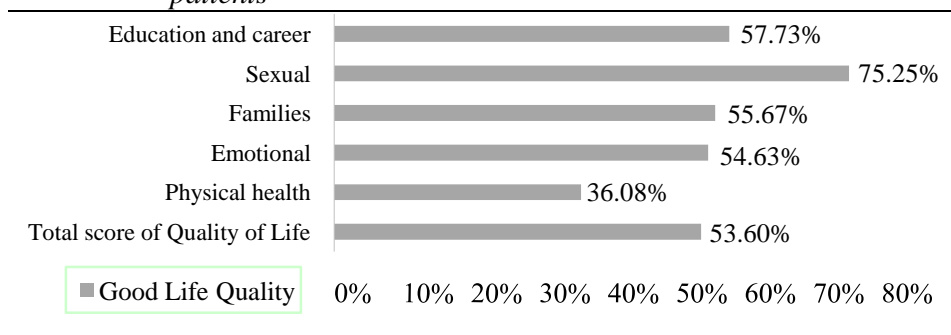
	Total score of QoL	Physical health	Emotional	Sexual	Families	Education and career
Age of mothers	$r = .09$ $p = .34$	$r = .09$ $p = .37$	$r = .15$ $p = .14$	$r = .06$ $p = .50$	$r = .01$ $p = .90$	$r = -.05$ $p = .62$
Age of children	$r = .18$ $p = .07$	$r = .11$ $p = .26$	$r = .22$ $p = .02^*$	$r = .16$ $p = .10$	$r = -.13$ $p = .89$	$r = .04$ $p = .66$
Disease duration	$r = .18$ $p = .07$	$r = .05$ $p = .58$	$r = .21$ $p = .03^*$	$r = .10$ $p = .29$	$r = .03$ $p = .75$	$r = .05$ $p = .57$
Number of family members	$r = -.12$ $p = .21$	$r = .01$ $p = .88$	$r = -.14$ $p = .15$	$r = .09$ $p = .34$	$r = .03$ $p = .71$	$r = -.13$ $p = .19$
<i>M ± SD</i>	74.59 ± 13.56	77.57 ± 20.24	70.86 ± 14.57	85.56 ± 28.60	82.84 ± 15.67	76.85 ± 20.33

p -value was obtained from the Spearman test results.

*The comparison was considered significant when $p < .05$.

The mean QoL dimensions of the caregivers became the limits for grouping them in good and bad quality of life levels. Therefore, the QoL was good when it presented a score above the average for each dimension of quality of life. The general description of the quality of life based on the categorization determined from the mean value is shown in Figure 1. Interestingly, caregivers' quality of life in the physical health dimension scored the lowest value compared to the other QoL dimensions (see Fig. 1 for more details).

Figure 1 – The good Quality of Life level of caregivers of thalassemia patients



As shown by the Mann-Whitney test, a significant relationship was found between the income level of the participants and the family dimension of the caregiver's quality of life ($p = .04$; refer to Tab. 3 for more details). Thus, the higher the income level of the parents, the more the family needs were fulfilled, avoiding possible family conflicts. In contrast, the education level did not show significant relationships with any of the dimensions of the caregiver's life quality ($p \geq .05$).

Table 3 – *Relationship between education and income level on the Quality of Life (QoL) dimensions for caregivers of thalassemia patients*

	Total Score of QoL	Physical health	Emotional	Sexual	Families	Education and career	
Education Level	High School <i>M ± SD</i>	74.24 ± 13.73	77.41 ± 19.68	70.48 ± 14.64	85.78 ± 28.05	82.27 ± 16.07	76.87 ± 20.59
	Equivalent College <i>M ± SD</i>	77.98 ± 11.93	79.16 ± 26.51	74.56 ± 14.17	83.33 ± 35.35	88.50 ± 9.75	76.66 ± 18.70
	<i>p</i> -value	.58	.67	.42	.96	.31	.83
Income Level	< UMP <i>M ± SD</i>	72.57 ± 14.30	79.68 ± 17.14	69.44 ± 14.46	82.50 ± 30.59	78.39 ± 18.54	76.12 ± 21.67
	≥ UMP <i>M ± SD</i>	76.01 ± 12.96	76.09 ± 22.19	71.85 ± 14.69	87.71 ± 27.19	85.97 ± 12.54	77.36 ± 19.52
	<i>p</i> -value	.28	.55	.41	.31	.04*	.81

< UMP = Under Provincial Minimum Wage (< Rp1.810.350); ≥ UMP = Above Provincial Minimum Wage (≥ Rp1.850.350).

The *p*-value was obtained from the Mann-Whitney test.

*The comparison was considered significant when $p < .05$.

6. Discussion

The differences in each individual's characteristics affect the level of quality of life (Piran *et al.*, 2017).

The results of this study proved that there was a correlation between the age of children with thalassemia and the quality of life of the caregiver in the emotional dimension ($p = .02$). The emotional dimensions measured were feelings of guilt, anxiety, annoyance, hopelessness, and disturbance because of children's health problems. Our results were in line with previous research conducted in Iran on the caregivers of children with chronic diseases, which reported that children's age influenced the caregiver's life quality (Piran *et al.*, 2017). This happens because the younger the child is,

the more attention and support is needed. Therefore, caregivers experience limitations in carrying out their activities, which increase their burden and reduce their quality of life due to the inability to achieve their goals and life plans as a result of limited physical activity as well as the correlated stress experienced (Piran *et al.*, 2017). Thalassemia, unfortunately, is a disease that cannot be permanently cured. Moreover, the sufferer needs to undergo a number of transfusions to survive, covering his/her whole lifespan (Septyana, Mardhiyah, & Widiyanti, 2019). Thus, the caregiver's emotional condition needs further attention because it plays an important role in providing medical support to children affected by a disease lasting a lifetime (Astarani & Siburian, 2016).

The results of this study also highlighted a correlation between disease duration and caregivers' life quality in the emotional dimension ($p = .03$). The long duration of the disease brings to feelings of hopelessness and anxiety because of the child's condition that needs to continuously receive medication, as well as complications experienced by sufferers, such as changes in the face shape, skin color, splenomegaly, stunted growth, and development (Mediani, Tiara, & Mardhiyah, 2019).

Previous research has shown that other risk factors, such as the mother's age, were also associated with the quality of life of caregivers of thalassemia patients (Piran *et al.*, 2017; Mediani *et al.*, 2019). As described by previously published reports, the mother's age was included in the final adult or reproductive age group based on the respondents' characteristics (Amin & Juniati, 2017). Age, in fact, was shown to affect a person in expressing his/her feelings and on how to deal with the disease (Mediani *et al.*, 2019). Young mothers are generally more prone to a decreased life quality due to psychological problems, one of which is anxiety (Mashayekhi, Jozdani, Chamak, & Mehni, 2016). Anxiety concerning the condition of sick children makes the caregiver pay more attention, especially in younger mothers.

In contrast to previous reports, we did not find a correlation between the mother's age and the caregiver's quality of life. This may be explained by the fact that in our dataset mothers were mostly mature (18-40 years old). Mothers with a mature age are better at coping with difficulties and at adapting to the situation than younger mothers. They, thus, tend to avoid psychological problems, such as anxiety, that affect their life quality (Vellyana, Lestari, & Rahmawati, 2017).

Previous research has also shown that the number of family members can affect the quality of life of thalassia patients' caregivers (Piran *et al.*, 2017;

Mediani *et al.*, 2019). The more the number of children in a family, the higher the stress level experienced by the caregiver, because of the increasing role in providing care (Mediani *et al.*, 2019). Therefore, family support in the form of financial, emotional, informational, and instrumental aids is also important to reduce the burden of care, which impacts on the life quality of the caregiver (Nurvinanda, Mulatsih, Hartini, & Nurjannah, 2019). In this study, the average number of nuclear family members was ideal (4 people). When the number of children in a family is smaller, in fact, the caregiver has more time to dedicate to his/her social activities (Piran *et al.*, 2017). The supportive social conditions provide strength and reduce the pressure in providing care, which has a positive impact on the caregiver's quality of life (Nurvinanda *et al.*, 2019).

A chronic disease with a progressive course has a long-term debilitating effect on psychosocial health, not only on the patient, but also on the caregiver. As previously reported, the fluctuating patients' condition during treatment and therapy caused moderate to severe stress in more than half of the population of caregivers (Alvarez-Avellon, Arias-carrion, & Gonzalez, 2015). Moreover, the impact of the treatment does not only affect the child but also the caregiver with an increase of the impact related to disease duration, as long as it is more than five years (Marnis *et al.*, 2018). In this research, the average disease duration was more than eight years.

The longer duration of the disease, in turn, leads to a financial burden for caregivers in providing care to children, especially those characterized by a low socioeconomic status (Mediani *et al.*, 2019). In our dataset more than half of the subjects had a fairly high-earning level, namely the West Java Provincial Minimum Wage (UMP). The results of our research indicated a relationship between the income level and the quality of life of caregivers in the family dimension ($p = .04$), in line with previous findings ($p < .001$; Biswas, Sarkar, & Haldar, 2020). Income is considered an indicator of family welfare because caregivers with high incomes tend to avoid conflict and disharmony in the family (Leng, Xu, Nicholas, Nicholas, & Wang, 2019). A good income fulfills the caregiver's needs in obtaining the necessary resources for child care and in coping better in raising children with special needs (Dewi & Mu'in, 2015).

The decrease in the caregiver's quality of life, due to the increase in burden experienced by taking care of sick children, is generally due to psychological problems (Astarani & Siburian, 2016). Previous findings have shown that the psychological problems experienced are mainly caused by a

financial burden because thalassemia requires a prolonged and routine treatment (Miskam, Juhari, & Yaacob, 2017).

Furthermore, the COVID-19 pandemic has also affected the financial burden because many workers have lost their jobs and income due to the economic impact of this deleterious sanitary condition (Hadiwardoyo, 2020). Losing a job has exacerbated caregivers' financial burden, thus causing psychological problems and reducing their life quality (Rakhmilla *et al.*, 2020). In addition, the loss of income and economic hardship may lead to economic stress and marital conflict (Schneider, Harknett, & McLanahan, 2016). Several reports worldwide have, in fact, indicated a significant increase in domestic violence since the emergence of the COVID-19 pandemic (Graham-Harrison, Giuffrida, Smith, Ford, Connolly, Jones *et al.*, 2020). Quarantine has reduced freedom and privacy, consequently adding more stress to couples in their relationship. Exposure to domestic violence, in turn, has significantly affected children's mental health, especially thalassemia sufferers. Since the emergence of the COVID-19 pandemic, children and teenagers worldwide have been exposed to a greater risk in violence due to conflicts in their parents' marriage or conflicts between family members. The current lack of community supervision and limited access to child protection services are additional burdens.

In addition, the impact of a pandemic also implies facing an economic recession. The impact of an economic recession on children at this time is a threat to children's and teenagers' mental health. In this case, thalassemia sufferers face an even more severe economic pressure. This concept was reinforced by a study, which directly assessed teenagers' mental health during the financial crisis in Greece. The researchers found that there was an increase in the mental health problems of teenagers during periods of recession (Paleologou, Anagnostopoulous, Lazaratou, Economou, Peppou, & Malliori, 2018).

Moreover, disruption to the caregiver's quality of life was also caused by physical stress. In this study, the description of a good quality of life in caregivers had the lowest proportion in the physical dimension. This may be explained because the caregiver experiences fatigue, lack of energy, pain and discomfort, as well as difficulty in sleeping due to the increased burden of caring for sick children (Yengil, Acipayam, Kokacya, Kurhan, Oktay, & Ozer, 2014).

The caregivers' life quality was also influenced by the education level (Piran *et al.*, 2017). Those with a high knowledge and education were found to have a more effective method in dealing with problems and in

overcoming anxiety, meeting their emotional needs (Mediani *et al.*, 2019). This reduced the caregiver's problems related to stress, therefore improving their life quality and preventing possible burdens. Based on the analysis of our results, in contrast to previous findings, there was no relationship between the education level and the dimensions of caregivers' life quality ($p \geq .05$). Previous research reported that a person's knowledge is obtained through formal and non-formal education. This occurs because the current development of information technology helps caregivers collect information on their children's health problems and to use it to overcome their stress problems (Ray, Rahmawati, & Andhini, 2019).

The life quality according to health (health-related quality of life) describes a series of multidimensional and functional components, such as physical, psychological, and social factors, perceived by a person (Ismail, Chun, Shahar, Manaf, Rajikan, Mohd Yusoff *et al.*, 2013). A person with a good quality of life is an individual who carries out functions and roles on a daily basis (Karimi & Brazier, 2016). The caregivers of thalassemia patients generally experience stress and disturbances in their life quality, which are affected by the disease (Abdullah, Idris, Shamsuddin, & Abdullah, 2019; Biswas, Naskar *et al.*, 2020). The life quality of caregivers is a determining factor in the success of the treatment of the disease because it plays an important role in providing direct care and support to children. However, the assessment of this factor has received still little attention and priority during the care process. The pandemic conditions have forced people to comply with social distancing, have increased the pressure on families, and have reduced access to health services. The economic recession, the consequences of anxiety, stress, and exposure to violence are the main problems that are currently faced as well as the difficulty in administering treatments in terms of routine transfusions. Based on these results, we used a routine life quality assessment to prevent and detect at an early stage psychosocial problems, such as depression, anxiety, and despair in caregivers. Therefore, the intervention was carried out without having an impact on the children's life quality. However, the current pandemic is increasing stress and disrupting the life quality for both sufferers and caregivers. This condition, on the other hand, gives an opportunity to introduce an innovative approach in providing counseling services through telemedicine, resulting in a safe and more efficient coverage of the target population from the available resources.

The results of this research, although promising, still have some limitations. For example, collecting the interview data via telephone makes it difficult to directly assess the seriousness of the answers given by the

subject. Moreover, other risk factors, other than the subject's sociodemographic characteristics, should be further explored in future investigations.

7. Conclusions

The risk factors of thalassemia patients' age and illness duration affected the caregiver's life quality in the emotional dimension, while the income level had an impact on their QoL in the family dimension. The caregiver's quality of life is a determining factor for the success of sufferers treatment; therefore, an innovative approach, in the form of counseling services through telemedicine, is advised in the current pandemic condition. This intervention is required for the prevention and early detection of psychosocial problems in caregivers. Therefore, it does not have an impact on children's life quality.

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