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ORIGINAL RESEARCH

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RELATIONSHIP OF ADHERENCE, SELF EFFICACY, SOCIAL SUPPORT, QUALITY OF HEALTH CARE, AND PSYCHOLOGICAL RESPONSE OF PARENS TOWARDS QUALITY OF LIFE OF CHILDREN WITH TUBERCULOSIS IN YOGYAKARTA, INDONESIA

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ABSTRACT

Background: Quality of life includes the aspects of physical, emotional, social function, welfare and perceptions about life. Quality of life of children with tuberculosis is considered lower than the quality of life of healthy children. Little is known about the factors related to the quality of life of children with tuberculosis, especially in Yogyakarta, Indonesia.

Objective: This study aims to examine the relationships of adherence, social support, quality of healthcare, self-efficacy, and psychological response of parents towards quality of life of children with tuberculosis in Yogyakarta, Indonesia.

Methods: This study employed a cross-sectional correlation design, which was conducted from April to November 2016, and involved 41 caregivers and children with tuberculosis according to research criteria. A consecutive sampling was applied to determine sample size. Data were analyzed by bivariate and multivariate analysis using SPSS with significant level $p=0.05$ and confidence interval = 95%.

Results: Findings showed significant relationships between social support, psychosocial response, mainly anxiety and stress ($p<0.05$) with quality of life. While adherence, self-efficacy, and quality of healthcare did not have significant relationship ($p>0.05$) with quality of life. The results of multivariate analysis showed significant relationships between social support with $r=0.305$ (CI95%:0.134-0.188; $p=0.026$), psychosocial response of caregiver, mainly level of stress with $r=0.425$ (CI95%:-1.369-0.126; $p=0.007$) and anxiety with $r=0.378$ (CI95%: -0.107-1.692; $p=0.03$) and quality of children life (R square=0.278). The strongest variable related to quality of children life was psychosocial response (anxiety) of parents ($r=0.425$).

Conclusions: Quality of life in children with tuberculosis is related to social support and psychosocial response of parents. The dominant factor is psychosocial responses of anxiety.

Keywords: quality of life, children, tuberculosis, related factors

INTRODUCTION

Long-term therapy is required for children with tuberculosis. It is because the medication consists of Fixed Dose Combination (FDC) packages, which contains multidrug and needs more than 6 months to complete the medication. Indirectly, long-term therapy increases depression, mood disorders, and fatigue that impact quality of life.^{1,2} Literature also indicated that patients with tuberculosis aged 20-55 had low quality of life.³ However, quality of life is related to health indicators that affect physical aspect, psychological, social aspect, and life function.

Tuberculosis (TB) is an infectious disease that attacks a respiratory tract. It is a communicable disease, and the second killer after HIV/AIDS in the world. The highest mortality related to TB's patient mortality in 2010 was in Asia, which was 60% of global mortality.⁴ The Global Tuberculosis Report of WHO (2014) showed prevalence of TB on 2011 in Indonesia attained the 5th rank in the world after India, Nigeria, Pakistan, Bangladesh.⁴ Globally, incidence of tuberculosis on 2013 estimated 9 million and amounts more five hundred thousand cases suffered to children.⁵

Survey result estimated that the prevalence of tuberculosis in children in Indonesia about 5%-6% of total cases in a year.⁶ It is more than five hundreds thousands of children in 2014 suffered from tuberculosis, and the global mortality attained more than seventy thousand or about 8% of total mortality. Based on the result of preliminary research, the incidence of TB on children in Yogyakarta was high (8% per 100.000 population), and the current data reported 37 cases tuberculosis on children.^{4,5}

In this study, the quality of children's life includes the assessment of physical, emotional and social function.⁷

Physical function refers to the assessment towards physical activity, energy, power and fitness; emotional function refers to the assessment towards depression status, mood and stress; and social function refers to the assessment of the relationship between TB's patient with other people (neighbor, friends etc.).

The quality of life of children with tuberculosis should receive more attention due to the impact of the disease for children and their families, such as the difficulties in the integration with peers, anxiety, and family dysfunction.⁸ In addition, the communication with peers and parent-child relationships generally will also be disrupted.⁹

Factors affecting the quality of life of children include family, health and social environment,¹⁰ so if these factors remain positive, the quality of life of the children might be increased. It is in line with the previous research indicated that the factors affecting the quality of life of children were a behavioral disorder during infancy, health status, mother's mental health, social support, family support, and parenting.¹¹

Family factors become an important factor to strengthen the quality of children life with tuberculosis, such as the medical adherence of parents, self-efficacy, psychological response of the children, social support, and health care support as external factors.

Adherence is an agreement between medical doctor and patients regarding their medication. In the context of pediatric nursing, adherence was the complex process due to the decision making of the children towards medication and treatment were dependent on the parents.¹² The level of parent's adherence could impact the recovery of the children. Thus, the role of the parents in providing the properly care is needed.

Second, self-efficacy of parents is

the belief regarding self-ability as a parent in providing positive health care to the children.¹³

Third, psychological factors include the emotional reaction and attention of the parents. Another factor is social support both internal or external factors such as family, friends, neighbor or health workers.¹³ The quality of life is an important indicator to assess the success of the intervention of health care provided in addition to the morbidity, mortality, fertility and disability.

Nurses and other health providers play an important role in improving the health status and the quality of life of children with tuberculosis. However, little is known about the study about the quality of life on children with tuberculosis in Indonesia, especially in Yogyakarta, Indonesia. Therefore, this study aimed to examine the factors influencing the quality of life on children with tuberculosis.

METHODS

This was a correlational study with cross sectional design. It was conducted from April to November 2016. There were 41 parents having children with tuberculosis were recruited by consecutive sampling. The instruments used in this study were social support of caregiver questionnaire modified from Social Support Questionnaire (SSQ) of Sarason et al,¹⁴ adherence questionnaire developed based on the adherence concept and treatment for TB's patient according to the good governance of tuberculosis launched by WHO,⁴ Ministry of Health of Indonesia,² IDAI,¹⁵ and CDC cit. Gonzalez et al.¹⁶ The other instruments were Parental Stress Scale (PSS) by Berry & James, and Psychological Well-Being Index (PGWBI) that focuses only the anxiety domain to

measure the psychological response of caregiver,¹⁷ Cooper Parental Self-Efficacy Scale-Child Health Behavior (CPSS-CHB) for self-efficacy, PedsQL Generic Core Scales Versi 4.0 to measure the quality of life of children, and the modified instrument of quality of health care services. The validity and reliability of all instruments were examined to 31 respondents before data collection. The results showed the good validity and reliability with coefficient correlation $r=0.402-0.921$ and alpha on interval $0.702-0.78$.¹⁸

Data were analyzed using univariable analysis, bivariable, and multivariable analysis. The univariate analysis calculated mean score, categorized in the high, medium, and low level using the formula, indicated that low with $X < (\text{Mean} - 1.0 \text{ SD})$, medium with $\text{Mean} - 1.0 \text{ SD} \leq X < (\text{Mean} + 1.0 \text{ SD})$, and high with $X \geq (\text{Mean} + 1.0 \text{ SD})$.¹⁹ Spearman correlation test was also implied for this study.

Ethical approval was obtained from the Ethics Committee of Faculty of Medicine, Gadjah Mada University in April 2016. Prior to the data collection, informed consents were obtained from the respondents.

RESULTS

Characteristics of the respondents

There were 41 spouses of parents (caregivers) were recruited in this study, with children (aged 0-18 years old) suffered from tuberculosis in Yogyakarta, Indonesia. Table 1 showed that the respondents consisted of fathers (2.4%) and mothers (98.6%). Of 73.2% respondents were young adult and most of them (5.7%) had senior high school background.

Table 1 Characteristics of the Respondents (n=41)

Characteristics	Frequency	Percentage (%)
Gender		
Male	1	2.40
Female	40	98.60
Relationships with Children		
Father	1	2.40
Mother	40	98.60
Age		
Young adults (21-40 years)	30	73.20
Middle Adulthood (40-65 years)	11	26.80
Education		
Primary Education (Elementary to junior high School)	8	19.50
Secondary Education (High School)	22	53.70
College education (D1/D2/D3/D4/S1/S2/S3)	11	26.80

The children suffered from tuberculosis in this study included toddler, children and adolescents. Table 2 showed that toddler group was the most suffering group with tuberculosis (17.07%) than the other groups. The amount of the drugs that the

children need to take per day was mostly more than 3 tablets. Data also showed that children have the other families such as father, grandmother, grandfather and aunty (beside mother) to control their medication.

Table 2 Characteristic of Children with Tuberculosis (n=41)

Characteristics	Frequency	Percentage (%)
Age		
Toddlers (>5 years)	14	58.54
Child (5-11 years)	10	24.39
Adolescents (12-20 years)	7	17.07
Gender		
Male	25	60.98
Female	16	39.02
Length of treatment		
Early phase	11	26.83
Advanced phase	30	73.17
PMO besides mother		
Yes	34	82.93
No	7	17.07
Amount of drug per day		
1x1 tablets	10	24.39
1x2 tablets	12	29.27
1x3 tablets	13	31.71
1x4 tablets	6	14.63
Support givers		
Nothing	1	2.44
Main family	10	24.39
Extended family	30	73.17

Description of the quality of life of children with TB

Quality of life of children suffered from TB is defined as the status of individual

related to the optimization of body function on the level of development and the feeling that is related to physical, emotional and social function. The quality

of life of children is viewed by comparing the total scores, the highest score on quality of life was in social function, and

the lowest score was in the emotional function. The other three aspects were in the low-medium level (Table 3 and 4).

Table 3 Quality of Life Score of Children suffered from Tuberculosis (n=41)

Quality of Life	Quality of Life Score		
	Minimum	Maximum	Mean±SD
Physical function	53.10	100.00	85.98±12.68
Emotions functions	42.00	100.00	73.82±16.01
Social functions	50.00	100.00	89.87±13.66
Total of function	50.00	100.00	79.58±12.65

Table 4 Level of Quality of Life of Children with Tuberculosis (n=41)

Quality of Life	Level of Quality of Life			Total n(%)
	Low n(%)	Medium n(%)	High n(%)	
Physical function	6(14.63)	32(78.05)	3(3.00)	41(100)
Emotion functions	10(24.39)	27(65.85)	4(7.32)	41(100)
Social functions	9(21.95)	32(78.05)	0(0.00)	41(100)
Total of function	3(7.32)	30(73.17)	8(19.51)	41(100)

Description of parents' adherence in providing care and quality of life of children

The description of parents' adherence in providing care and quality of life of children is described in Table 5.

Table 5 Level of adherence of parents in providing care of children with TB (n=41)

Aspect of Adherence	Quality of Life Score		
	Minimum	Maximum	Mean±SD
Medication adherence			
Low	65.38	90.38	77.79± 9.4
Medium	55.77	100.00	82.76±13.94
High	50.00	84.62	73.31±11.09
Nutritional adherence			
Low	22.00	25.00	23.80±1.30
Medium	26.00	30.00	28.06±1.22
High	30.00	30.00	30.00±0.00
Infection control adherence			
Low	19.00	22.00	21.22±1.09
Medium	23.00	29.00	26.04±1.74
High	29.00	30.00	29.71±0.30
Adherence of caring			
Low	68.00	75.00	72.85±2.67
Medium	74.00	85.00	80.53±2.95
High	86.00	90.00	88.25±1.48

Parent's adherence in providing care to the children is the level of parents' behavior on giving medication, providing adequate diet, and applying healthy life style as the prevention act and infection control. Table 5 describes the level of adherence of parents and quality of life of children with

tuberculosis. It can be concluded that the higher level of parent's adherence, the higher level of the quality of life of the children.

Description of the level of care quality and quality of life of children

The level of quality of care is the parents' assessment towards the quality of health provider in giving healthcare services to the patients. The assessment includes the aspects of technical components, access to

services, interpersonal relations, security and comfort. Table 6 shows that all levels of care quality almost have the similar score on the quality of life of the children.

Table 6 Level of Health Care Quality (n=41)

Care Quality	Quality of Life Score		
	Minimum	Maximum	Mean±SD
Low	61.54	88.46	76.68±10.09
Medium	55.77	100.00	80.97±12.43
High	50.00	100.00	77.74±16.75

Psychological response of parents and quality of life of children

Parents psychological response refers to the parent's emotional reaction and feelings. In this study, the psychological response is related to stress and anxiety levels. The higher total score obtained, the higher level of stress and anxiety levels of the parent, which indicated that the

response of parents is getting worse. Table 7 shows that the quality of children's lives is better with the parents who have low levels of stress. While the quality of life children is higher with the parents who have middle levels of anxiety compared with the level of higher and lower anxiety level of parents.

Table 7 The Psychological Response of Parents with Tuberculosis Children (n=41)

Psychological Responses	Quality of Life Score		
	Minimum	Maximum	Mean±SD
Stress response			
Low	84.62	100.00	94.23±7.36
Medium	61.54	100.00	79.79±11.74
High	50.00	92.31	74.70±12.58
Anxiety response			
Low	55.77	100.00	79.98±12.86
Medium	68.85	100.00	83.05±12.44
High	50.00	90.38	75.29±12.33

Self-efficacy level of parents and quality of life of children

Self-efficacy is the belief of the parents to their own competence as the parent, or perception of their ability to bring the

children with tuberculosis care in the positive direction. Table 8 shows that the quality of life of children is higher with the parents who have a medium self-efficacy.

Table 8 Self-efficacy of Parents with Children with Tuberculosis (n=41)

Self-efficacy	Quality of Life Score		
	Minimum	Maximum	Mean±SD
Low	55.77	100.00	79.80±16.89
Medium	61.54	100.00	81.17±11.58
High	50.00	88.46	75.76±11.79

The level of social support and quality of life of children

Social support in this study includes the level of social support satisfaction

perceived by parents in providing care to the children with tuberculosis. The results showed that the medium and high level of

social support have the same quality of life score.

Table 8 Social Support and Quality of Life of Children with Tuberculosis (n=41)

Satisfaction of Social Support	Quality of Life Score		
	Minimum	Maximum	Mean±SD
Social Support			
Low	55.77	84.62	69.87±9.47
Medium	50.00	100.00	81.39±12.97
High	65.38	90.38	80.38±10.12

Relationships of quality of life children with tuberculosis and its related factors

The result of bivariate analysis showed that social support, psychosocial response of caregiver (stress and anxiety) had

significant correlation with the quality of life of children with tuberculosis ($p < 0.05$) although the power of correlations was weak ($r = 0.291-0.378$).

Table 9 Bivariate Analysis of Factors Related to Quality of Life Children with Tuberculosis (n=41)

Variable	Mean±SD	r	p
Adherence of parents	80.73±5.39	0.23	0.838
Social support	128.43±26.33	0.291	0.012*
The quality of health care	74.08±5.17	0.183	0.253
Psychological response: anxiety	16.26±0.71	-0.378	0.015*
Psychological response: stress	20.46±0.94	-0.363	0.002*
Parents self-efficacy	121.65±10.83	0.069	0.541

*Statistically significant ($p < 0.05$)

The most dominant factor that influence the quality of life children with TB

The result of multivariate analysis on table 10 showed that factors related significantly with the quality of life children with TB were social support ($r = 0.305$; CI95%: 0.134-0.188; $p = 0.026$), psychosocial response of caregiver included level of

stress ($r = -0.425$ (CI95%: -1.369-0.126; $p = 0.007$) and anxiety ($r = -0.378$ (CI95%: -0.107-1.692; $p = 0.03$)). The most dominant variable that had the relationship with the quality of life of children with tuberculosis was psychosocial response (anxiety) of caregiver ($r = -0.425$).

Table 10 Multivariate Analysis of Factors Related to the Quality of Life Children with Tuberculosis

Variable	r	95%CI	p
Social support	0.305	0.134-0.188	0.026*
Psychological response: anxiety	-0.425	-1.369-0.126	0.007*
Psychological response: stress	-0.378	-0.107-1.692	0.03*

*Statistically significant ($p < 0.05$)

While table 11 showed that 27.8% (R Square = 0.278) of quality of life of children with tuberculosis was influenced by the variables of social support, psychosocial responses of parents, the

level of stress and anxiety contribute to the quality of children tuberculosis, while 62.2% of it were caused by other factors (Table 11).

Table 11 Child Social Support Tuberculosis (n=41)

Model	R	R Square	Adjusted R Square	Std. error of the estimate	p
Social support, psychological response of anxiety and stress on quality of life	0.527	0.278	0.220	11.17	0.007

*Statistically significant ($p < 0.05$)

DISCUSSION

This study showed that more than half of children suffered from TB who were involved in this study were toddlers (ages 0-5 years old), and most of them took advance medication with 3 tablets per day, and controlled by their mothers and other family members.

The incidence of TB among toddlers is still high. Ministry of Health of Indonesia mentioned that one of the factors increasing the number of TB is the low immune system.² The number of male children with TB is higher than the female children.²⁰

Children with tuberculosis requires long-term treatment, and it may affect the quality of children's life. Quality of life according to Preedy & Watson research (2010) was not limited to the physical, social and emotional function, but also welfare or feelings about life.²¹

In this study, the quality of life in emotional function was lower than the quality of life in physical and social function. Emotional functions included the feelings of fear and anxiety, sadness, irritability, and insomnia. Findings showed that more than half of respondents sometimes felt angry easily, and nearly half of the respondents also encountered sleep disturbances and felt fear. This psychological condition occurred when the child was in poor condition. Those who experienced TB would have respiratory problem that might affect the emotional function, such as feeling angry easily and having emotional uncontrolled.²²

Adherence is defined as the rate at which patients follows the instructions given to them in determining of treatment

and decision making related to the treatment time from the commencement to the termination of therapy.²² In this study, data showed that the higher the level of adherence of parents, the higher level the quality of life of children. But, the bivariable analysis indicated that there was no relationship between parent's adherence and the quality of life of children with tuberculosis. This finding is not in line with the pattern of nursing care by parents that is related to the quality of life.²¹ This result might be affected by some other factors associated with quality of life of children, such as health care, home environment, family social relationships, social support, self-efficacy, and psychological response.^{7,23,24}

On the other hand, findings in this study showed that there was no significant relationship between parents' views about the quality of care and quality of life of children. It means that health service does not affect the quality of life of children with tuberculosis. It is because the quality of health services does not directly affect the quality of life of children, but the quality of health care provider is closely related to adherence of parents in providing care of the children.

The effort of parents to improve the quality of life of children is associated with their psychological responses. In this study, psychological response of parents includes stress and anxiety levels. Findings showed that the higher score the level of stress and anxiety, the lower the level of the quality of life of the children. Statistical analysis showed that parental psychosocial response had significant relationship with the quality of life of

children. This relationship occurs because parents are the primary care givers for the children. Case Western Reserve University stated that the parent-child specific disease reported they experience stress at the sight of child in pain.²⁵ In general, parents' stress is not related to the length and severity of illness, but more related to when the child is in sick and pain period,^{26,27} which may be able to make the parents desperate.²⁷

Literature stated that the parents often feel anxious with the development of their children, treatment, regulation, a state in the hospital, and costs of care.²⁸ These responses can be caused by chronic disease in children, less favorable of treatment, and economic level of the family. Information for parents should be given continuously based on the stage of development of the children condition to reduce the anxiety of parents.²⁹ In this study, the quality of life of children was higher with the group of parents with medium anxiety level. It is in line with previous study mentioned that anxiety in an individual may provide the motivation to achieve something, and it is important sources in an effort to maintain the balance of life. In this case, the parents have a strong desire to improve the quality of life of children as directed by health workers.³⁰

In this study, the quality of life of children is also higher with the parents who had medium level of self-efficacy, compared to the parents who had low and high level of self-efficacy. Parental self-efficacy is parental belief to their own competence take care of the children, or parental perception of their ability to bring the children in the positive direction. The results of this study showed that there was no significant correlation between parental self-efficacy and quality of life of children. It might be self-efficacy is directly related to the compliance of parents than to the quality of life. Parents with good self-efficacy show good adherence to

treatment, which is important for parent as a caregiver who supervises and provides care for children with tuberculosis to recover. Otherwise, parents who have low self-efficacy will have an impact on psychology, health, behavior, and affect the treatment process.

Another factor is the social support received by the parents in taking care of the children with tuberculosis. More than half of respondents received medium social support. Literature indicated that the informational support has a significant effect on patients' serious illnesses.³¹ It is also stated that the greatest social support received by patients with TB is from family members and health care workers.³² Statistically, there was a significant relationship between social support and quality of life of children tuberculosis in this study. Social support from medical personnel to provide optimal health services can improve the quality of life of the children. In this study also indicated that factors such as social support, and psychological response, mainly stress and anxiety had 27.8% contribution in affecting the quality of life of children with TB.

CONCLUSION

Social support and psychological response of parents, both stress and anxiety are related to the quality of life of children with TB. The dominant factor that is related to the quality of life children with TB is psychological response of parents, especially the level of anxiety. Future research is needed to examine the internal and external factors towards quality of life of children with TB.

Declaration of Conflicting Interest

None declared.

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Authorship Contribution

All authors equally contributed in this study and agreed with the final approval of the article.

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