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Quality of Life in Down Syndrome Children with Hypothyroidism During Covid-19 Pandemic

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Abstract

Down syndrome (DS) children with hypothyroidism are elevated risk for psychological disturbances and this risk has been compounded by the COVID-19 pandemic. Therefore quality of life is very important to be evaluated. The aim of this study is to evaluate factors influencing quality of life (QoL) among DS children with hypothyroidism during the COVID-19 pandemic. A cross-sectional study of 30 DS children with hypothyroidism (aged 2-18 years) was conducted from April-July 2021 by Pediatric Endocrine Outpatient Clinic of Dr. Soetomo Hospital. Participants were evaluated using The Peds QoL Generic core which evaluates physical (p), emotional (e), social (s), and school (sc) functioning dimension. A score below 70 was considered indicative of poor QoL. Differences in dimensional and total scores were evaluated among age groups, between sexes, and according to physical activity levels, number of siblings, parental education level, and parental employment status using Spearman's test, Mann-Whitney U-test, or independent-samples t-test as indicated. 30 DS children with hypothyroidism included in the study. Mean scores for all dimension was 58.3, whereas mean score for each dimension: p; e; s; sc was (54.1; 63.8; 56.6; 61.6) respectively. There was a significant difference between boy and girl on median phyisical functioning dimension score (57.8 vs 45.9) but not emotional, social, or school functioning dimension score. There was also a significant correlation between age and emotional functioning dimension (P=0.02; r=-0.4). Participants aged 2-4 years demonstrated lower mean scores than older children (57.2). DS children with hypothyroidism are experiencing poor QoL during COVID-19 pandemic, specially in the physicial dimension. Interventions hould focus on opportunities for safe physiical activity.

Keywords : Down syndrome, hypothyroidism, children, quality of life.

1. Introduction

Coronavirus disease-2019 (COVID-19) that causes Severe Acute Respiratory Syndrome – Coronavirus 2 (SARS-Cov-2) infection is an ongoing global pandemic that has killed millions of people and disrupted the lives and livelihoods of mllions more. The high risks of mortality for

certain vulnerable populations and the public health measures to limit transmission (lock-downs) have led to a sharp increase in mental illnes. Further, it has greatly impeded the management of chronic diseases such as Down's syndrome (DS). Indeed, while social isolation may be an effective stategy to prevent infection and virus transmission, social interaction is an important aspect of DS management as it contributes to improved quaity of life (QoL). Therefore, social isolation is a major challenge for DS patients.(Russo et al., 2020).

The prevalenceof hypothyroidism 28 times higher in DS than the normal population. Thyroid dysfunction is reported around 50% of DS children mostly are overt and subclinical hypothyroidism. Nonetheless, DS children need to visit hospital for routine medical check-ups and lifelong L-thyroxin dose adjustment.(Amr, 2018).
The COVID-19 pandemic has complicated the situation for DS children and their families by creating barriers to health services. This situation will influence the quality of life for both DS children and their families.(Pedrosa et al., 2020).

2. Significance of The Study

Hypothyroidism in DS children need to visit hospital to do routine medical check-ups and COVID-19 pandemic situations can make the condition more complicated and influence the quality of life both the patients and families.

3. Review of Related Studies

A previous study reported decreases in emotional and physical aspects QoL among DS children before COVID-19 pandemic. (Haddad et al., 2018; Lee et al., 2021). The older children with DS and hypothyroidism showed better social function QoL than emotional QoL, in accord with Xanthopoulos and colleagues, who reported that youth with DS scored poorer on psychosocial health than youth without DS, providing further evidence of relatively poor emotional well-being among this group. (Xanthopoulos et al., 2017).

4. Objective of The Studies

The aim of this study is to determine the impact of the COVID-19 pandemic on quality of life among DS children with hypothyroidism.

5. Hypotheses of The Study

There is an impact of the COVID-19 pandemic on quality of life in DS children with hypothyroidism.

6. Population and Sample

A cross-sectional study was conducted at Pediatric Endocrinology Outpatient Clinic Dr. Soetomo Hospital from April to July 2021. Inclusions criteria were DS patients aged 2-18 years, diagnosed with hypothyroidsm, and signed informed consent by the parents. This study was approved by the ethics committee of Dr. Soetomo General Hospital, Surabaya, Indonesia.

Participant age, parent's educational background and employment status, sex, number of siblings, and levels of daily activity in a week were evaluated. Physical activity (sport, dance, and game play for more than 20 minutes) was recorded for a week based on parental recall via telephone interview during study. Parents were interviewed using the Indonesian version of the Peds QoL questionnaire. The Validity of the English version was demonstrated by Viecili,&Weiss (2015). Meanwhile in Bahasa Indonesia version by Wardin.(Wardin, 2016). The Peds QoL instrument was used to examine factors reducing QoL among DS children with hypothyroidism during the COVID-19 pandemic. The peds QoL contains two sections, one for parents, the other one for children. There are also age group specific classifications (2-4, 5-7, 8-12, 13-18 years). The parents report was used for all subjects. Four functional dimensions of QoL were analyzed in this study: physical (p), emotional (e), social (s), and school (sc).

In this study, participants were divided into 4 age groups based on 4 domains in Peds QoL questionnaire. The parents were interviewed about their child's physical, emotional, social, and school domains. All domains were answered on 5-point Likert scale from 0 (Never) to 4 (Almost always): 0 (Never), 1 (Almost never), 2 (Sometimes), 3 (Often), and 4 (Almost always). Scores were transformed on a scale from 0 to 100 s follows: 0=100, 1=75, 2=50, 3=25, 4=0. Children with score < 70 were rated as having a poor quality of life.

6.1.Statistical Techniques Used in the Present Study

Scores and other variables were first examined for normality using the Kolmogorov-Smirnov test. Scores were compared among age groups,according to parent's educational level, number of siblings, weekly activity levels using Spearman test. Correlation between sex and parent's emplyoment status were analyzed using the non-parametric Mann-Whitney (abnormal distribution) and Independent t test (normal distribution). $P \leq 0.05$ was considered significant for all tests. All statistical analyses were conducted using Collected using *Statistical Product and Service Solution (SPSS) for Windows version 25.0.*

6.2.Data Analysis and Interpretation

Table 1. Characteristics of DS children and their parents

	Characteristic	N (%)
Sex	Boy Girl	20 (66.7%) 10 (33.3%)
Age	2-4 years	18 (60%)
	5-7 years	8 (26.7%)
	8-12 years	4 (13.3%)
	13-18 years	0 (0%)
Mother's education	Primary school	3 (10%)
	Junior high school	3 (10%)
	Senior high school	13 (43.3%)
	Diploma	3 10%)
	Bachelor	8 (26.7%)
Father's education	Primary school	1 (3.3%)

	Junior high school	4 (13.3%)
	Senior high school	12 (40%)
	Diploma	3 (10%)
	Bachelor	10 (33.3%)
Mother's emplyoment status	Working	10 (33.3%)
	Not working	20 (66.7%)
Father's emplyoment status	Working	27 (90%)
	Not working	3 (10%)
Number of children	1 child	7 (23.3%)
	2 children	15 (50.0%)
	> 2 children	8 (26.7%)
Activity per week	0-2 days	1 (3.3%)
	3-4 days	16 (53.3%)
	≥ 5 days	13 (43.3%)

Interpretation of Table-1.

Baseline characteristics of the participants are presented in Table 1. All DS children were 12 years or younger. Physical activities included exercising, dancing, and playing reported for more than 20 minutes.

Table 2. Quality of life dimension scores based on age

No	Age	Physical	Emotional	Social Functioning	School	Mean
1	2-4 years	50.7	66.7	53.8	75.0	57.2
2	5-7 years	58.8	58.8	61.3	50.0	59.2
3	8-12 years	60.1	61.3	60.0	61.3	60.7
4	13-18 years	0.0	0.0	0.0	0.0	0.0
Mean		56.5	62.2	58.4	62.1	59.0

Interpretation of Table-2

Based on age classification, The 2-4 years group had the lowest quality of life than the others, indicated by the lowest mean score (57.2).

Table 3. Quality of life dimension scores

Peds QoL dimension	**N**	**Mean**	**SD**
Physical	30	54.1	12.6
Emotional	30	63.8	7.5
Social functioning function	30	56.6	8.2
School	6	61.6	11.7

Interpretation of Table -3

Scores for each aspect of pediatric quality of life are shown in Table 3. Mean quality of life score was less than 70 points for every domain, with lowest mean score for the physical activity domain.

Table 4. Comparisons of QoL scores by sex and parental employment status

Characteristic	All Aspects	Physical	Emotional	Social function
Sex				
Boy	59 (6.5)	57.8 (26-71.9)	63.1 (7.28):	58.3 (40-75)
Girl	56.6 (6.0)	45.9 (25-62.5)	65.3 (8.2)	62.5 (45-66.6)
p-value	0.35*	**0.012****	0.47*	0.22**
Mother's emplyoment status				
Working	63.3 (4.7)	60.5 (9.4)	68.8 (60-70)	60.9 (6.9)
Not working	55.6 (5.5)	50.9 (12.9)	63.8 (43.7-80)	54.4 (8.0)
p-value	**0.01***	**0.04***	**0.04****	**0.036***
Father's emplyoment status				
Working	57.9 (6.5)	56.2 (25-71.9)	65 (43.7-80)	58.3 (40-75)
Not working	61.4 (3.95)	55 (43.8-70)	68.8 (65-68.8)	58.3 (58.3-65)
p-value	0.36*	0.91**	0.34**	0.44**

*) Independent sample-t test

**) Mann-Whitney Bold type= significant

Interpretation of Table-4.

Various QoL dimension scores differed according to the child's sex and parent's employment status. Physical aspect dimension was significantly influenced by both boy and girl. Mother's employment

status had influence on QoL score, while the school aspect could not be examined due to the small number of subjects who attended school.

Table 5. Correlations between participant characteristics ands Ped QoL**.**

Characteristic	**All aspects (r;p)**	**Physical (r;p)**	**Emotioanl (r;p)**	**Social functional (r;p)**	**School**
Age group	0.12; 0.523	0.28; 0.12	**-0.40; 0.028***	**0.36; 0.045***	-0.14; 0.79
Mother's education	-0.11; 0.54	-0.15; 0.41	-0.16; 0.39	-0.98; 0.6	-0.36; 0.48
Father's education	-0.02; 0.92	-0.18; 0.93	-0.17; 0.36	-0.11; 0.55	-0.4; 0.43
Number of children	0.17; 0.38	0.21; 0.26	0.05; 0.78	0.04; 0,84	**0.85; 0.03***
Physical activity per week	0.1; 0.58	-0.09; 0.61	-0.11; 0.54	**0.4; 0.03***	-0.4; 0.43

*) $p < 0.05$

Interpretation of Table-5

The older children with DS and hypothyroidism demonstrated a poorer emotional quality of life but a better social quality of life. Social QoL was improved by increasing the number of physical activities per week.

Overall quality of life has been poor for DS children with hypothyroidism during the COVID-19 pandemic. Further, poor QoL was found in all domains, while a previous study reported dereases in emotional and physical aspects QoL among DS children before COVID-19 pandemic.(Haddad et al., 2018; Lee et al., 2021). A study in 2017 found decreased QoL among DS children except in emotional functioning.(Xanthopoulos et al., 2017). Therefore, the pandemic appears to be having a further detrimental effect on DS children, especially by limiting opportunities for physical activity.

From our study, boys were reported to have a better quality of life in the physical aspect than girls. Consistent with previous research which states that boys had a better score in quality of life in physical aspect than girls.(Brodani & Kovacova 2019). Boys are more active than girls at all ages measured using various self-report tools. (Thompson et al., 2003). Some parents are less supportive of physical activity of girls than boys.(Sallis et al., 1992). Further, boys may be more assertive about activities than girls .(Norris et al., 2001).

The older children with DS and hypothyroidism showed better social function QoL than emotional QoL, in accord to Xanthopoulos and colleagues, who reported that youth with DS scored poorer on psychosocial health than youth without DS, providing further evidence of relatively poor emotional well-beingamong this group. (Xanthopoulos et al., 2017). Significantly, levels of emotional well-being among adolescents aged 13-21 years compared to young children aged 4-5 years.(Lee et al., 2021). Adolescents with DS also show a greater propensity for internalizing symptoms.(Gameren-oosterom et al 2013; Grieco et al., 2015). The older children in our study group had better social function QoL than the younger. Likely due to greater linguistic ability as a previous study found that higher receptive vocabulary scores predicted fewer social problems in DS children.(Næss.2016).

Mother's employment status was associated with all domains of the child's QoL as well as the mother's QoL. A permanent job, can improve social life as well as mental health and psychosocial status. (Gibson-Davis & Gassman-Pines 2010). Many mothers must devote so much time and energy to their DS child that they have no time for relaxation or personal enjoyment, leading to mood swings, low self confidence, and reduced social participation.(Huiracocha et al., 2017). Parents of children with greater impairments also experience greater depression. Theoretically, maternal depression will also reduce QoL of children with special needs.(Gibson-Davis & Gassman-Pines 2010). However, parents of children with DS have reported greater well being than parents of other intellectually disabled children even though they may be anxious and afraid after first receiving the DS diagnosis. It is important that the health system and community organizations work with parents to improve the QoL of both children with DS and their parents. (Marshall et al., 2015; Skotko. 2005; Stoneman. 2007).

Children participating in a greater number of activities per week scored higher on the social function aspect of QoL, consistent ith the finding of Haddad and colleagues that better better functioning in activities of daily living was associated with improved QoL. Furter, children participating in physical activity 3 or more days pe week had higher QoL scores than those who were inactive (0-2 days per week). Sebire and colleagues reorted a positive association between social acceptance and physical activitiy among boys. (Sebire et al., 2011). Active children exhibit more well-developed social skills including lower aggression, lower withdrawal, and greater sociability than less active children. It has also been reported that adolescents who have difficulty making friends report lower physical activity than those who find friends easily. (Newcomb et al., 1993; Page et al., 2007). In addition, peer problems, emotional symptoms, hyperactivity, and conduct problems n children are associated with lower levels of physical activity. (Hamer et al., 2009). Children with who have supportive and encouraging friends to their physical activities will be more physically active and demonstrate better social-emotional and social cognitive skills than children without such support. (Davison. 2004; Gifford-Smith & Brownell 2003; Hohepa et al., 2007; King et al., 2008; Panter et al., 2010).

7. Recommendations

- This study can provide information regarding the impact of the COVID-19 pandemic in Down syndrome children with hypothyroidism.
- This study can be used to improve the quality of life of down syndrome children with hypothyroidism.

- Further study is needed to identify the quality of life of DS children with hypothyroidism so the study can be able to conduct early intervention to achieve optimal quality of life.

8. Conclusions

DS children with hypothyroidism in Indonesia are experiencing uniformly poor quality of life during COVID-19 pandemic. There is no different between boy and girls except physical function.

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