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ORIGINAL ARTICLE

Quality of life and comprehensive health supervision for children with Down syndrome in Thailand

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Abstract

Children with Down syndrome often require several specialty doctors and multidisciplinary teams for their associated anomalies. This may impact their quality of life and creates gaps in treatment monitoring. No studies have yet been conducted in Thailand to measure their quality of life and level of comprehensive health supervision. Therefore, we aimed to study the quality of life among children with Down syndrome and determine if they receive comprehensive health supervision for their condition. In this descriptive research, data were collected from a medical record review of children with Down syndrome during a 1-year period in our Pediatric Outpatient Clinic; 50 children and 39 caregivers participated. Mean total quality of life score of the children was 67.9/100 points. The children had the highest scores (73.6 ± 12.8) in emotional functioning and the lowest (57.2 ± 25.6) in cognitive functioning. It appears that the quality of life may be lower in Down syndrome patients than in Thai children without it. Regarding health supervision, all 50 were screened for thyroid function, and 48 received cardiac evaluations. However, only 17 (34%) received "complete basic assessment" of 5 screening combinations with developmental evaluations and growth monitoring. Furthermore, none received "comprehensive" evaluations for all recommended conditions. While these findings show a need for health supervision improvement for children with Down syndrome within our hospital, they may also be indicative for most care facilities throughout Thailand.

Keywords Children with Down syndrome · Quality of life · Comprehensive care · Health supervision

Introduction

Down syndrome is the most frequently encountered chromosome abnormality and the most frequent cause of developmental delay/intellectual disabilities in children (Pace et al. 2011; Sherman et al. 2007). The World Health Organization (2018) states the worldwide incidence rate is 1:1000–1100 in newborns. In Thailand, approximately 1100 newborns were born with Down syndrome in 2014 (Pangkanon et al. 2014). Children with Down syndrome usually have intellectual impairments accompanied by multiple congenital anomalies such as cardiac defects, thyroid abnormalities, hearing/vision impairments, bowel stenosis/obstruction, hematologic abnormalities, spine and joint laxity, and delayed growth (Bull and Committee on G 2011; Stoll et al. 2015). Thus, these children are patients requiring complex care due to the need for monitoring and investigation across several physiological systems.

Most anomalies, such as small bowel obstructions or cardiac defects, are congenital. However, some, such as thyroid dysfunction and vision or hearing impairments, can occur later in their lives. Some anomalies are obvious, while others can only be diagnosed with further investigation. For example, early stages of certain cardiac defects or thyroid hypofunctions require investigations to detect them as their symptoms are not yet present. Other anomalies require treatment to prevent permanent complications.

Therefore, comprehensive health supervision, not just specific care for any single symptom, should be provided for children with Down syndrome; this would ameliorate their current and future conditions and may also improve their

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quality of life. The guidelines on health supervision for these children in Thailand follow those of the American Academy of Pediatrics (AAP: Committee on Genetics 2001). The AAP guidelines cover infancy to 21 years of age, as well as diagnosis and screening recommendations for complications at various ages. The goal is for children with Down syndrome to receive comprehensive medical care. With this, they should reach adulthood capable of self-care and be able to participate in society.

While the AAP guideline is being used in Thailand, there have not been any studies to evaluate the level of care received, especially given health care service limitations; the amount of available physicians for patients; and the use of laboratory investigations. In Thailand, we have less than 20 geneticists and no genetic counselor. Almost all children with Down syndrome are monitored by general pediatricians with varying knowledge and comfort in care for these children. Thai pediatricians generally treat at least 30–50 children a day. This reality presents challenges in how comprehensive care can occur in this system.

Children with Down syndrome are at higher risk for developing multiple comorbidities, which will affect the well-being of children and their families. Quality of life (QoL) is one method used to evaluate well-being. While it is subjective, it provides some understanding of an individual's perception of his/her well-being. Pediatric QoL was developed to measure children's well-being, using their own perspective, at specific ages in several domains (Eiser and Morse 2001). Currently, the Pediatric Quality of Life Inventory™ (PedsQL™) 4.0 is the standard generic core scale of QL to measure the physical and psychosocial health of either healthy or ill children (Varni et al. 2001). However, children with chronic diseases were found to have a lower QoL than children without chronic diseases in several countries (Jonsson et al. 2017) as well as in Thailand (Pongwilairat et al. 2005; Duangchu et al. 2014; Sritipsukho et al. 2013). Other studies reported children with Down syndrome to have a lower QoL in physical health, problem-solving functions, and social functions; however, they displayed no differences in emotional functioning from other children (van Gameren-Oosterom et al. 2011; Xanthopoulos et al. 2017).

We do not yet have any research on QoL among children with Down syndrome in Thailand. At present, there is only one study conducted on the QoL of parents caring for children with Down syndrome (Wunsayukha 2010), which found multiple effects on parental QoL as the care required was more time-consuming than that for children without Down syndrome. For example, parents reported being unable to work fulltime, but the greatest impact was on parents' physical health.

We attempted to explore QoL among children with Down syndrome treated at Thammasat University Hospital (TUH) and to determine whether they received comprehensive health care supervision as recommended in the AAP guidelines for Down syndrome.

Methods

A descriptive research study was conducted over 1 year, between June 2016 and May 2017. Data were collected by medical chart review of children with Down syndrome treated at the Pediatric Outpatient Clinic (OPD) of TUH, prior to any visits to a Down syndrome clinic or genetic clinic. Details gathered included children's age and gender, genotype of Down syndrome, their comorbidities, and management/treatment. Further information on parents (age, gender, relationship to child, educational level, occupation, household income, marriage status) and QoL of the children was obtained by a verbal questionnaire given to parents (1 parent per child) when their children were visited at Pediatric OPD. This study was approved by the Institutional Review Board 1, Thammasat University (Faculty of Medicine), Project Code: MTU-EC-PE-1-040/59. Parental informed consent (and children's assent if they were older than 7 years and able to understand) was signed before questionnaires were administered by the researcher.

Children's quality of life scores were measured by using the PedsQL™ 4.0 generic core scale with permission from the Mapi Research Trust. The questionnaire was translated into the Thai language, which was previously tested for reliability and accuracy for QoL among Thai children (Sritipsukho et al. 2013). The questionnaire was age specific and divided into 6 groups: infants aged 1–12 months and 13–24 months; children aged 2–4 years, 3–5 years, 5–7 years, and 8–12 years. The questionnaire was given to the parents; however, children aged 8–12 years were also given the questionnaire if they were capable of completing it. Questions covered the following four areas: physical health (function and symptoms) and psychosocial health, including emotional, social, and cognitive/school functioning. There was a total of 23 questions, having a five-point rating scale (range of 0 to 4 points based on the agreement in each statement). The scores were transformed into full scores of a maximum of 100 points in each area: 100 points meant good QoL with no problems, while 0 points meant QoL with nearly constant problems. The total scores from each functional area were the average scores from the answered questions. Unanswered questions were omitted. If more than 50% of the questions were unanswered, scores were not calculated. Total scores for QoL were average scores of the 4 functional areas.

The survey of health supervision was modified based on the recommendations of the AAP guidelines on 12 screening conditions. First, patients were considered to have a "complete basic assessment" if there was any medical records in all of the following 7 conditions/screenings: cardiac defect, thyroid

Table 1 Demographics of children with Down syndrome and their caregivers

Children's characteristics	**Total: 50 children**	
	Number of patients	**Percentage (%)**
Gender: male	26	52
Age (year)		
Under 1	16	32
1–3	16	32
Over 3–6	13	26
Over 6–10	4	8
Older than 10	1	2
Mean (SD)	3.03 (2.9)	
Genotype		
Trisomy 21	46	92
Unbalanced translocation	3	6
Mosaic	1	2
Siblings with Down syndrome	4 (from 2 families)	8
Number of siblings (including patient)		
No sibling	14	28
2–3 siblings	18	36
More than 3 siblings	3	6
Caregivers' characteristics	**Total: 39 caregivers**	
	Number of caregivers	**Percentage (%)**
Gender: male	7	18
Age (year)		
25–35	15	38
Over 35–45	18	46
Over 45–55	3	8
Older than 55	2	5
Mean (SD)	38.8 (7.5)	
Relation to the child with Down syndrome		
Father	7	18
Mother	29	74
Cousin	3	8
Educational level		
None	1	3
Primary school	7	18
Secondary school	13	33
Diploma	6	15
Bachelor's degree	9	23
Master's degree or above	1	3
Occupation		
Housewife	15	38
Daily laborer/temporary employee	9	23
Contract/permanent employee (private industry)	6	15
Business owner/self-employed	8	20
Government employee	1	3
Household income per month (baht)		
Less than 10,000	6	15
10,000–25,000	12	31
25,000–50,000	11	28
More than 50,000	4	10
Marital status (only for parents)		
Living together	30	77
Separated	3	8
Divorced	2	5

Table 2 Quality of life assessment scores in children with Down syndrome, categorized by age

Age	Number of patients	Physical health scores/100 (lowest-highest scores, SD)		Psychosocial health scores/100 (lowest-highest scores, SD)			Mean of all scores (lowest-highest scores, SD)
		Physical functioning	Physical symptomatology	Emotional functioning	Social functioning	*Cognitive/school functioning	
1–12 months	10	66.4 (29.1–91.6, 24.5)	73.5 (55–90, 10.2)	77.1 (42.1–86.6, 14.1)	75.6 (31.2–100, 14)	55.6 (18.7–87.5, 30.0)	69.4 (56.1–88.3, 10.8)
13–24 months	6	74 (52.7–88.9, 15.2)	72.5 (60–92.5, 14.9)	78.1 (66.7–83.3, 7.9)	79.7 (70–87.5, 7.2)	35.4 (22.2–44.4, 13.9)	66.6 (54.1–75.6, 9.6)
2–4 years	12	67.7 (18.8–100, 28.5)		71.6 (45–90, 15)	63.3 (25–100, 25.7)	72.3 (41.7–100, 23.2)	64.7 (32.2–86.8, 16.4)
5–7 years	6	60 (40.6–81.3, 16.2)		66.7 (45–80, 14.4)	62.5 (30–95, 25)	41.9 (25–62.5, 17.5)	58.2 (31.3–75.3, 18.9)
8–12 years (proxy reporting)	6	75 (34.4–100, 24.6)		73.9 (58.3–85, 12)	83.3 (60–100, 18.6)	59 (30–90, 27)	77.3 (51.1–89.7)
8–12 years (self reporting)	4	74.7 (62.5–96.9, 15.8)		77.5 (75–85, 5)	67.5 (15–100, 40)	65.5 (41.7–85, 18.9)	70.8 (62.3–86.7, 11.1)
Total	44	69.4 (18.8–100, 20.2)		73.6 (42.1–90, 12.8)	71.5 (15–100, 24.3)	57.2 (18.7–85, 25.6)	67.9 (31.3–88.3, 14.5)

*Cognitive functioning is used for children under 2 years of age; school functioning for those over 2 years of age

function, complete blood count (CBC), visual screening, auditory screening, development/learning assessment, and growth monitoring, as these conditions are designated as essential to be monitored in children with Down syndrome of every age from birth. Second, if the following additional 5 conditions were assessed and recorded in the medical chart: cervical spine subluxation, breathing problems or sleep apnea, frequent upper respiratory tract infections, assessment of the presence or absence of abnormal constipation, and dental assessments, it would be considered as a "comprehensive assessment."

Developmental capabilities were assessed with the Capute Scales for children at developmental ages under 3 years. The assessments consisted of the Capute Linguistic and Auditory Milestone Scale (CLAMS) and the Capute Adaptive Test (CAT). Scores should generally be related to patients' age; however, among children with delayed development, scores were found to be equal to the developmental quotient (Visintainer et al. 2004). The Wechsler Intelligence Scale for Children (WISC-III) was used for children with developmental ages of above 6 years. The assessment scores indicated an intellectual quotient.

Results

From a total of 93 eligible children with Down syndrome, 43 children were excluded due to the absence of chromosomal confirmation or only limited data in medical records. Therefore, 50 children with Down syndrome were included. They were aged 2 months to 12 years with a mean age of 3.03 years and similar numbers of male and female. All children had chromosomal analysis to confirm Down syndrome diagnosis, in which 46 had trisomy 21, 3 had unbalanced Robertsonian translocation, and 1 had mosaic trisomy 21. Of the 50 children, 4 were siblings: 2 with unbalanced translocation and identical twins with trisomy 21.

There were 39 Thai parents who completed the questionnaires. One family had twins, so there were 39 parents for 40 children. Another 9 parents (for 10 children which included 2 siblings with Down syndrome) were not available for participation due to time constraints. Most of them (74%) were mothers, 18% were fathers, and 3 main caregivers (2 grandparents and 1 sister). They aged between 25 and 56 years with a mean age of 38.8 years. All of them had no experience in caring for children with Down syndrome. Most of them graduated from high school or lower, were stay-at-home parents, and raised their children themselves; 59% of them had mean monthly family incomes within a range of 10,000–50,000 Thai baht. Most were married and living together (Table 1).

The QoL survey was conducted among 40 children. Data were collected from one parent per child, with one parent answering for twins. Only 4 children, aged 8–12 years, could

Table 3 Health supervision evaluation data for children with Down syndrome

Evaluation parameters*	Children receiving investigations		Children with abnormal results after investigations	
	Number of patients	Percentage (%)	Number of patients	Percentage (%)
Congenital heart diseases	48	96	33	69
Thyroid abnormalities	50	100	17	34
Hematological abnormalities	45	90	7	16
Gastrointestinal abnormalities	31	62	11	35
Ophthalmological/visual defects	41	82	18	44
Auditory/ear defects	43	86	24	56
Respiratory tract problems (sleep apnea, snoring included)	7	14	2	29
Cervical spine issues	2	4	0	0
Growth monitoring (i.e., malnutrition, etc.)	21	42	4	19
Dental care screening**	12	35	8	67
Developmental assessment	30	60	30	100

*Parameters adapted from American Academy of Pediatrics[7]

**Using 34 children only over 1 year of age; dental care screening performed by a dentist

complete the questionnaires by themselves. Their total mean quality of life score was 67.9 out of 100, with a minimum score of 31.3, a maximum score of 88.3, and a standard deviation of 14.5. The mean emotional functioning score was found to be the highest at 73.6 (42.1–90 ± 12.8), followed by social functioning. Cognitive and school functioning was the lowest at 57.2 (18.7–85 ± 25.6). The 4 children who completed the questionnaires themselves revealed higher scores in emotional and school functioning, similar scores in physical health, and lower scores in social functioning as compared with the reports by their parents (proxy reporting), as shown in Table 2. However, there was no difference in the total mean scores between the children's reports (70.8 ± 11) and parents (77.3 ± 14.6): P value = 0.38.

In health supervision, all patients (100%) had thyroid function tests, and almost all patients (96%) were assessed for congenital heart diseases, having a physical examination with echocardiograms performed by pediatric cardiologists. Ninety percent (90%) of patients were screened for hematological abnormalities; of these, 76% were assessed during the 1-year period. Another 86% had undergone auditory screening, while 82% were assessed for vision. For the evaluation of cervical spine subluxation and breathing conditions/snoring, only 4% and 14% had been monitored, respectively. Only 17 patients (34%) were found to have received "complete basic assessment," while none received "comprehensive assessment."

Assessment results most frequently revealed congenital heart diseases (69%), followed by auditory impairments (56%), visual defects (44%), and thyroid disorders (34%). Interestingly, although only 12 of 34 children aged over 1 year had their teeth examined by dentists, 67% of these children were found to have tooth decay (Table 3). The details of all anomalies are shown in Table 4. Developmental assessment in 30 children, aged less than 6 years, was examined with the Capute Scales. The CLAMS scores were within 21–150 points, having a mean of 64, while the CAT scores ranged from 0 to 96 points with a mean of 52. Total scores (developmental quotient) were 24–90 points with a mean of 58, which is considered as having mild developmental delay (Table 4).

After detection of anomalies or impairments, most children who required treatment received the appropriate management; 17 children with congenital cardiac defects were treated by surgery and oral medications, and 16 children having thyroid dysfunctions were treated with a thyroid or anti-thyroid supplement, as necessary. Half of the children had visual impairments and were treated by prescribing glasses. However, the area of dental assessments presented an interesting and important challenge as dentists, not doctors, were needed for treatment. Few patients were examined, but almost 70% had tooth decay.

Discussion

This appears to be the first study in Thailand to assess both the quality of life and comprehensiveness of health supervision for children with Down syndrome. The children's average quality of life score was 67.9 ± 14.5, which is lower than the 79 ± 12.8 points in Thai children without Down syndrome. However, it was similar to a quality of life score for children with chronic diseases such as heart diseases, asthma, and thalassemia, who had a mean score of 69 ± 14.8 according to a previous study (Sritipsukho et al. 2013). Most of our respondents reported that these children had good emotional

Table 4 Detailed abnormalities identified in children with Down syndrome in the present study

Specific abnormalities	Number of children affected	Percentage of abnormalities
Congenital heart diseases		
AVSD/VSD/ASD	22	67
PDA	3	9
VSD with PDA	4	12
DORV, PA	2	6
PHT	1	3
Coronary sinus fistula	1	3
Total	33	100
Thyroid abnormalities		
Hypothyroid	12	71
Hyperthyroid	1	5
Hyperthyrotropinemia	4	24
Total	17	100
Hematological abnormalities		
Anemia	6	85
TAM	1	15
Total	7	100
Gastrointestinal abnormalities		
Duodenal atresia	3	27
Constipation	4	36
Hirschsprung	1	9
GERD	2	18
Jaundice	1	9
Total	11	100
Ophthalmologic/visual defects		
Refractive errors	15	83
Nystagmus	2	11
Undetermined	1	6
Total	18	100
Auditory/ear defects		
Hearing impairment	21	88
Referred for further hearing tests	2	8
Ear canal stenosis	1	4
Total	24	100
Snoring/obstructive sleep apnea	2	100
Malnutrition	4	100
Dental caries	8	100
Developmental delay/intellectual disabilities		
Severe (DQ < 30)	4	13
Moderate (DQ 30–50)	5	17
Mild (DQ 51–70)	13	43
Borderline (DQ 71–90)	8	27
Total	30	100

AVSD, atrial septal defect; *VSD*, ventricular septal defect; *ASD*, atrial septal defect; *PDA*, patent ductus arteriosus; *DORV*, double outlet right ventricle; *PA*, pulmonic atresia; *TAM*, transient abnormal myelopoiesis; *GERD*, gastroesophageal reflux disease; *DQ*, developmental quotient

responses, which mirrors previous studies (van Gameren-Oosterom et al. 2011; Xanthopoulos et al. 2017) that confirmed highest scores were in the emotional functioning domain for children with Down syndrome.

Our survey also revealed high social functioning scores. Cognitive and school functioning scores were lower than those in other areas, delineating significant deficiencies in these domains for these children. There was no clinically significant difference between QoL self report (70.8 scores) and proxy report (77.3 scores), similar to the study on Thai QoL reliability (Sritipsukho et al. 2013). This may imply that although the QoL questionnaire is a subjective assessment, these parents may have a somewhat accurate perception of their children's well-being. Both previous studies on QoL for children with Down syndrome (van Gameren-Oosterom et al. 2011; Xanthopoulos et al. 2017) were caregiver reported. QoL of children reported by parents may be corresponding to the QoL of their parents, given the relationship between them in the same family (Cuskelly et al. 2008). We are the first study with self-reported QoL in children with Down syndrome, although we only had 4 children who reported.

Medical record reviews were assessed for comprehensive health supervision. Pediatrics residents were the main physicians for the children. Screening for thyroid functions, cardiac and hematological abnormalities, and auditory and visual impairments was done in most children with Down syndrome. Growth monitoring and developmental assessments were performed in less than half of the patients. Only 34% of children were receiving "complete basic assessment" care. Interestingly, none received a "comprehensive assessment" based on the AAP health supervision guidelines.

There are several possible explanations. First, doctors and parents were initially concerned with the presenting symptoms, often in specialty clinics, when there were actually multiple problems or anomalies, some not readily apparent. The second may be that doctors were not aware that the risk for these associated anomalies is higher for this particular patient demographic. Third, the doctors may have actually performed these assessments but simply did not note down the anomalies in their records. Last, there is also a lack of information for parents to be aware of this type of monitoring needed from childhood until adulthood (Henderson et al. 2007; Minnes and Steiner 2009). Our findings are limited to our university hospital, where we are training for resident and general doctors. Therefore, we may have a greater amount of time to spend per patient with better resources, investigations, and supervising staff versus general (provincial or community) hospitals. There is still a lot of doubt regarding health supervision for children with Down syndrome in other settings.

Our study revealed cardiac defects in 66% of children with Down syndrome, which was higher than those of previous studies (Bull and Committee on G 2011; Stoll et al. 2015). The main reason for this may be that our hospital is a cardiac referral center for neighboring hospitals. Treatment after detection was appropriate for nearly all patients, with most expenses universally covered by the government. However, dental problems remain a critical issue in children with Down syndrome as dental decay can introduce infective endocarditis, a serious infection in patients with cardiac anomalies.

Our limitations include a small sample size, as we had only 50 children and 39 caregivers to participate; the precision of actual versus reporting questionnaire of QoL for children; and missing information in medical records, which is an established problem with medical record review. While this is one small study, confined to our hospital, it provides at least one lens on this complex issue and can be a starting point for further research.

Conclusion

Although our children with Down syndrome had lower mean QoL versus children without, the scores mirrored that of Thai children with other chronic diseases. Notably, only one-third of our children received "complete basic assessment" while none received a "comprehensive assessment" based on the AAP guidelines. Health supervision for children with Down syndrome needs to be greatly improved and broadened. Physicians must be reminded of the importance of comprehensive health supervision for Down syndrome patients in our hospital and in our country.

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Compliance with ethics guidelines

Conflict of interest The authors declare that they have no conflicts of interest.

Ethical approval This study was ethically approved by the Institutional Review Board 1, Thammasat University (Faculty of Medicine), Project Code: MTU-EC-PE-1-040/59. All procedures performed in studies involving human participants are in accordance with the ethical standards of the institutional and/or national research committee and within the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed consent Informed consent was obtained from all parental participants included in the study before participation in questionnaires and interviews. Informed assent was obtained from individual children older than 7 years who were able to understand the questionnaires.

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