Original Article

Group Intervention Effects on Parental Attitudes Toward Children with Down Syndrome

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Background: Children with Down syndrome experience developmental delay and intellectual disability; however, parental attitudes make a world of difference. With appropriate care, most of these children have the potential for active social engagement as adults.

Objective: The present study aimed to determine whether group intervention might facilitate positive parental attitudes toward their children.

Materials and Methods: Parents of children with Down syndrome were enrolled during August 2016 to November 2017 and divided into a study and control group. Parental attitudes were evaluated at start and at least 6 months later.

Results: Thirty-five (35) parents were included: 18 in the study group and 17 in the control group. Median positive attitudes significantly increased after intervention in the study group (p = 0.01); however, they similarly increased in the control group (p = 0.02). Children's median total developmental scores rose in the study group but declined in the control group (0.96 vs. -6.14, p = 0.18).

Conclusion: It appears group intervention did not significantly affect parental attitudes. This may not mean group intervention lacks value as children within the study group displayed impressive developmental skill improvement.

***Keywords*:** Down syndrome, Attitude, Quality of life, Knowledge, Group intervention

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Down syndrome is the most frequent chromosomal abnormality and a cause of developmental delay/intellectual disability[1,2]. Worldwide incidence for live births with Down syndrome is currently 1: 800 to 1: 1,100[3,4]. The development and achievements of each child with Down syndrome is underpinned by various factors: comorbidities, childrearing practices, development promotion, etc. In families with more positive attitudes toward childrearing as well as greater understanding and acceptance, children tend to reach their maximum potential.

A study by Rooney found interactions with people with Down syndrome fostered better acceptance and attitudes from others toward those with the syndrome[5]. Similarly, Shobana and Saravanan demonstrated mothers of children with Down syndrome had more optimistic outlooks than mothers of children with autism and children with other mental disabilities[6]. However, parental attitudes toward Down syndrome seem to differ from prenatal to postnatal stages. In couples having prenatal aneuploidy screening, approximately 30 to 75% of them decided to terminate pregnancy if their fetus carried Down syndrome[4,7]. This contrasts with parents actually raising children with Down syndrome, who usually demonstrate acceptance and love for them[8].

Individual perceptions of the syndrome seem to improve with more exposure and knowledge[9]. A Thai study by Prof. Dr. Pornsawan Wasant and Dr. Chaiyan Rajchagoon demonstrated improvements in perceptions of and attitudes toward Down syndrome by providing several parental tools such as knowledge on Down syndrome itself, how to attain basic education rights for their children, and how to access better care; it also permitted parents to share their experiences during group intervention[10].

The authors aimed to determine whether group intervention could facilitate positive attitudes in parents of children with Down syndrome. The authors compared the proxy-reports of parental attitudes between study and control groups, before and after group intervention. In addition, the authors tried to elicit factors influencing parental attitudes, such as knowledge about Down syndrome, family income, and educational levels, as well as the children's level of development, quality of life, and overall health or

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comorbidities. Finally, the authors investigated at whether there were any changes in parental knowledge, their children's quality of life, and possible improvements in the children's development.

Materials and Methods

A non-randomized, controlled, interventional study with prospective patient preference and an interrupted time series was performed with parents of children with Down syndrome at Thammasat University Hospital, Thailand from August 2016 to November 2017. It was approved by the Human Research Ethics Committee of Thammasat University No. 1 (Faculty of Medicine: MTU-EC-PE-2-071/59). All parents of children aged 1 month to 6 years old with Down syndrome were included. The authors excluded parents who were unable to respond to questionnaires or did not complete both questionnaires; all eligible parents signed the consent form before enrollment. Participants were divided into two groups based on when they were enrolled. Parents enrolled before the second group intervention meeting and able to attend at least one meeting were placed into the study group. The remainder became the control group.

Group intervention sessions were held twice, each session being three hours. Activities consisted of discussions on the experience of having children with Down syndrome, understanding of the disorder, the relationship of parental stress with caregiving, training on relaxation techniques, and various childrearing strategies including child development evaluation and ways to stimulate/motivate their children. These activities were organized in cooperation with multiple health care professionals, including nurses with expertise in developmental issues, psychologists, child development pediatricians, pediatric geneticists, pediatric physical and speech therapists, pediatric residents, and medical students.

Data were collected using questionnaires on parental attitude, knowledge and proxy-reports on child's quality of life; children's development was evaluated with Capute Scales. Parental attitudes were assessed via an attitude questionnaire (Thai version) modified from previous studies[1,5] and evaluated for reliability using a pilot test of ten participants: Cronbach's alpha coefficient $\geq$0.7. Scores were calculated based on 39 questions/responses: 24 positive and 15 negative questions. Answers were expressed within a range of 1 to 4: 1 = "strongly disagree" to 4 = "strongly agree". Negative question scores were reversed. Higher scores represented more positive attitudes, with a top score of 156 points.

Parental knowledge about Down syndrome was assessed with a Thai questionnaire modified from previous studies; the content was validated by two experts. Its maximum score was 13, which meant having good knowledge.

Quality of life scores (QL) were assessed by the PedsQL (version 4.0) questionnaire, Thai version, tested for validity and reliability[11]; this was used with the permission of Mapi Research Trust (ID109215). It consisted of 23 items evaluating four key aspects: physical, emotional, social, and cognitive (for children $\leq$2 years old ow) or school functioning (in those older >2). The questionnaire is age-specific with six age divisions. The authors used four: infant, 13 to 24 months old, 2 to 4 years old, and 5 to 12 years old. Scores were based on only proxy-reports, and higher scores meant good QL.

Trained physicians and nurses used the 100-item Capute Scales to quantitatively measure the development of infants and children 3 years or below. The Capute Linguistic and Auditory Milestone Scale (CLAMS) is for language evaluation and the Capute Adaptive Test (CAT) for nonverbal problem-solving skills. Ideally, the CLAMS, CAT, and total raw scores, correlate with the child's chronological age[12]. Scores are standardized to a mean of 100 or developmental quotient of 100. High scores indicated good development. Children with Down syndrome normally express developmental delay, progressing at approximately half the rate of healthy children. Thus, the authors only enrolled children with Down syndrome under the age of 6 years.

All data were evaluated at the beginning of the study with re-evaluation at least six months after the first measurement. During the six months, the study group attended two group interventions. The control group received recommendations and were monitored based on commonly accepted standards of care for children with Down syndrome.

Statistical analysis included descriptive statistics with median comparing pre- and post-test attitude scores before and after group interventions. Wilcoxon rank-sum test and regression analysis were used to find correlations between factors affecting attitude. All analyses were performed using STATA (version SE14.0); $p\leq0.05$ was considered a statistically significant difference.

Results

Forty (40) parents of 31 children with Down syndrome were recruited, divided into the study group (19) and the control group (21). Five parents, 1 in the study group and 4 in the control group, were excluded due to missing follow-up for the second evaluation. Therefore, we had 35 parents:18 in the study group and 17 in the control (Figure 1).

Parental demographic data (gender, age, level of education, household income, occupation, as well as child's age) demonstrated no differences in both the study and control groups. Most parents included both a father and mother, and no parents had any previous experience with caring for children with Down syndrome. Likewise, demographic data of the children with Down syndrome (gender, age, and presence of comorbidities) were similar in both groups. Most children were $\leq$3 years old and had cardiac defects (Table 1). Parental attitudes, knowledge, self-reports of their child's QL, and developmental quotient (DQ) median scores between both groups were not divergent before the study (Table 2). Most parental attitudes, 85% (134/156) in the study and 83% (131/156) in the control groups, were considered "good" as the scores were over 80. Median parental knowledge scores were 8.5 and 8 out of 13, while children's QL scores were lowest in the psychosocial functioning domain. DQ scores revealed a moderate degree of deficiency. At the end of six

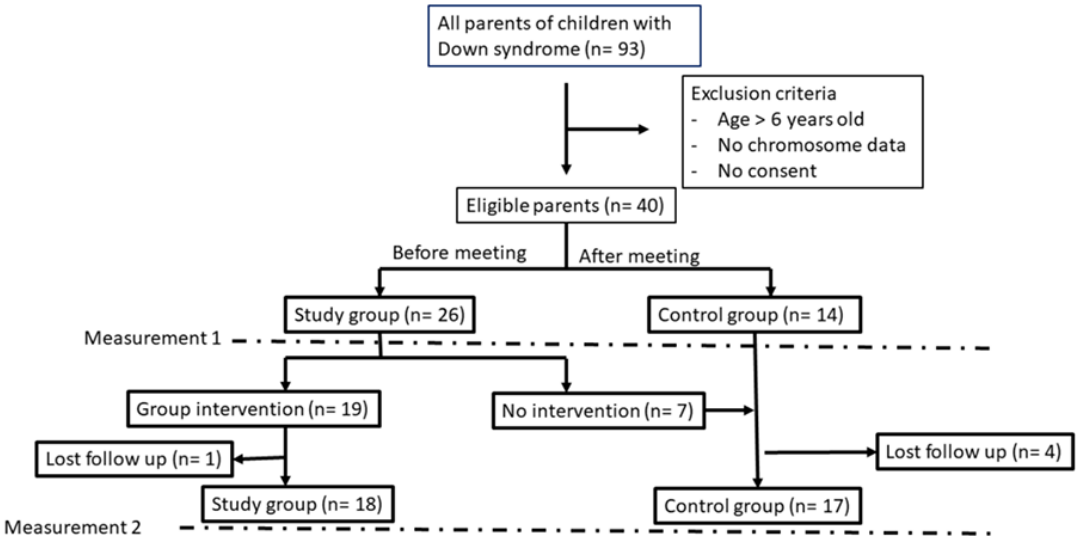

Figure 1. Research methodology: children with Down syndrome, karyotype confirmed, <6 years old were identified; parents were then contacted. If parents were enrolled before the second meeting and they attended group intervention, they were placed in study group. Parents who were enrolled after, or unable to join group intervention, were in control group. Measurements were done at enrollment and at least 6 months later for both groups.

months, parental attitudes and children's QL proxy-report scores appeared to increase with no distinctions between groups. However, children's developmental scores actually decreased in the control group, shown in Table 3.

Study group parents were found to have significantly higher attitude median scores ($p = 0.01$) while the developmental median scores of children with Down syndrome, children's QL by proxy-reports, and parental knowledge showed no difference. Parental attitudes and knowledge and children's QL scores in the control group were significantly higher ($p = 0.02$, 0.02 and 0.03, respectively). Development scores, however, were lower ($p = 0.09$): Table 4.

Discussion

Parental attitude median scores increased significantly in both the study and control groups, but group interventions did not appear to be a key factor influencing attitude changes. The increase in "good" parental attitudes overall may simply be due to the additional six months parents spent interacting with their children while receiving supportive care[13]. Of note, the children in our study were mostly <3 years; however, we are not sure whether this is a relevant factor or not. Other reasons for no apparent attitude changes might include considerations such as the group intervention topics: it is possible they were not particularly effective in or nor sufficiently targeted toward improving attitudes. Of note, our group interventions were only six hours and perhaps too few, being two sessions within six months. In addition, it is imaginable parents who concurrently took part in other group/individual activities outside our group, received information from outside consultants, or searched for information independently of doctors and professionals. Finally, the most relevant point may be that parental attitudes were already quite positive prior to any intervention: 85% for the study group and 83% for the control. We may have witnessed more dramatic results if parents had had much lower scores.

Apart from the impact of group interventions, Pace et al[1] revealed a positive relationship between parents who graduated with a bachelor's degree or higher and good attitudes toward Down syndrome; household income was not correlated in any way. In contrast, our study did not find any link between educational levels and positive attitudes. Perhaps this is because only 22% (8/45) of parents graduated with bachelor's degrees or higher; thus, we used high school or above as our cutoff. No other factors, in this study, had a positive correlation e.g. parental knowledge, children's associated anomalies, children's QL, or children's DQ.

Children in the study group seemed to have a more improvement in DQ versus children in the control. It is possible this is related to one of the featured topics in our group interventions, which was a workshop on developmental stimulation techniques. Interestingly, the DQ of children in the control group decreased afterwards. It is theorized that as children get older, the disparity gap between normal development and children with Down syndrome increases, especially if they do not receive adequate developmental stimulation i.e. developmental trajectory.

Table 1. Parental and children with Down syndrome demographic data in study and control groups

Parental demographic data	Study group (n = 18) mean (%)	Control group (n = 17) mean (%)	*p*-value
Gender: female	12 (67)	14 (82)	0.30
Age (years)			
35 or younger	5 (28)	9 (53)	0.64
Above 35	13 (72)	8 (47)	0.36
Education			
High school or below	9 (50)	9 (53)	0.63
Above high school	9 (50)	8 (47)	0.12
Household income (baht per month)			
25,000 or lower	12 (67)	10 (59)	0.11
Above 25,000	6 (33)	7 (41)	0.45
Relationship to child			
Father/mother	11 (61)	13 (76)	0.34
Cousins	7 (39)	4 (24)	0.59
Occupations			
Housewife	5 (28)	9 (52)	0.13
Company/government official	5 (28)	4 (24)	0.78
Business owner/merchant	8 (44)	4 (24)	0.20
Age of child with Down syndrome			
<1 year	8 (44)	7 (41)	0.85
1 to 3 years	8 (44)	6 (35)	0.59
>3 years	2 (12)	4 (24)	0.34
Previous experience on caring for children with Down syndrome:			
None	18 (100)	17 (100)	>0.05
Demographic data of children with Down syndrome	**Study group (n = 12) mean (%)**	**Control group (n = 15) mean (%)**	***p*-value**
Age (years)			
3 or younger	10 (83)	11 (73)	0.34
Above 3 years	2 (17)	4 (27)	0.34
Mean age (months; SD)	20 (±17)	24 (±23)	0.43
Gender: male	6 (50)	9 (60)	0.61
Associated anomalies			
Cardiac defect	10 (83)	12 (80)	0.92
Hypothyroidism	3 (25)	4 (27)	0.78
Hearing impairment	5 (42)	7 (47)	0.63

Parental knowledge at the beginning of the study averaged a score of 60% correct answers in both groups. Scores in the control group increased significantly at the end, presumably due to the direct knowledge they received and increased understanding. Previous research proxy-reported an average total score for child's QL in Thai "healthy" children as 79/100. By comparison, the average total score was 69 for children with chronic health conditions[11]. This was similar to our scores in both groups at the beginning.

The small sample size and number of group interventions indeed present clear limitations in our study. However, we may point out that this is the first study about parental attitudes on children with Down syndrome in Thailand, and it demonstrates a solid foundation upon which to build future research and understanding.

Conclusion

Although we had expected group interventions to play some role in affecting parental attitudes, this does not mean our group interventions, or any other ones, were and are not valuable. Future group interventions should be consistently held to assess longitudinal results and include more activities or participants. Newer and provocative topics for these interventions can be chosen and improved upon. While it is possible other positive changes may become apparent in the long term, the children of parents attending group inventions did show developmental gains. This prospect alone makes group interventions worthwhile.

Table 2. Comparison between study and control groups on the scores of parental attitudes and knowledge, children's quality of life and developmental scores at the beginning of study

Factors	Study group (n = 18)	Control group (n = 17)	*p*-value
Parental attitude scores	134.50	131.82	0.52
Parental knowledge scores	8.11	8.52	0.50
Children's quality of life scores proxy-reported (total)	69.01	65.82	0.49
Physical functioning	71.36	66.81	0.47
Emotion functioning	74.77	71.05	0.45
Social functioning	77.36	63.90	0.05
Cognitive functioning (≤2 years old)	52.43	63.19	0.32
School functioning (>2 years old)	79.17	68.15	0.53
Children's developmental scores (total)	58.77	60.68	0.76
CLAMS	65.69	66.36	0.94
CAT	51.85	55.00	0.67

CLAMS = Capute Linguistic And Auditory Milestone Scale, CAT = Capute Adaptive Test

Table 3. Comparison between the changes of parental attitudes and knowledge, children's quality of life and children's developmental scores in study and control groups

Factors	Changing scores		*p*-value
	Study group	Control group	
Parental attitude scores	9.33	9.82	0.89
Parental knowledge scores	0.61	1.18	0.42
Children's quality of life scores (total)	13.39	23.06	0.13
Children's developmental scores (total)	1.83	-8.96	0.09

Table 4. Comparison of parental attitudes and knowledge, children's quality of life and developmental scores in study and control groups at the beginning and then 6 months afterward

Factors	Study group			Control group		
	At the beginning	At 6 months after group intervention	*p*-value	At the beginning	At 6 months after group intervention	*p*-value
Parental attitude scores	134.50	143.83	0.002	131.82	141.65	0.003
Parental knowledge scores	8.11	8.72	0.27	8.53	9.71	0.01
Children's quality of life scores (total)	69.01	68.65	0.91	65.82	78.12	0.04
Children's developmental scores (total)	58.77	60.60	0.70	60.68	51.71	0.04

What is already known on this topic?

Interactions or experience with people having Down syndrome has led to better acceptance of them from others. Positive parental perceptions of Down syndrome encouraged these children to become high-functioning adults.

What this study adds?

Group intervention may not significantly affect positive parental attitude; however, group intervention still displayed benefits such as children's ameliorated developmental skills. Increased parental-child interaction, within a supportive environment, augmented "good" parental attitudes overall.

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Table 5. Factors associated with parental attitudes

Factors	Coefficient	*p*-value
Children's quality of life	0.27	0.85
Parental knowledge scores	-0.26	0.27
Children's developmental scores	-0.15	0.32
Children with associated congenital heart defects	6.42	0.27
Factors	**Mean attitude scores**	***p*-value**
Household income per month (baht)		
25,000 or below	131.0	0.28
Above 25,000	135.5	
Education		
High school or below	133.6	0.79
Above high school	132.5	

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Potential conflicts of interest

The authors declare no conflicts of interest.

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ผลของกิจกรรมกลุ่มต่อทัศนคติของผู้ปกครองเด็กที่มีกลุ่มอาการดาวน์

กิติวรรณ โรจนเนืองนิตย์, เพ็ญรวี ขาวสำลี, อิสราภา ชื่นสุวรรณ

ภูมิหลัง: เด็กที่มีกลุ่มอาการดาวน์แม้จะมีความบกพร่องทางพัฒนาการและเชาวน์ปัญญา แต่สามารถเติบโตพัฒนาและมีทักษะทางสังคมที่ดีได้เมื่อได้รับการเลี้ยงดูส่งเสริมการเรียนรู้และกระตุ้นพัฒนาการได้อย่างเหมาะสมจากผู้ปกครอง พบว่าทัศนคติของผู้ปกครองเป็นปัจจัยสำคัญในการเลี้ยงดูเด็ก โดยผู้ปกครองที่มีทัศนคติดีจะส่งผลให้เด็กได้รับการดูแลและเติบโตเป็นผู้ใหญ่ที่มีคุณภาพ

วัตถุประสงค์: เพื่อเปรียบเทียบว่ากิจกรรมกลุ่มมีผลให้ทัศนคติของผู้ปกครองที่มีต่อกลุ่มอาการดาวน์ดีขึ้นหรือไม่

วัสดุและวิธีการ: เป็นการศึกษาเปรียบเทียบคะแนนทัศนคติในผู้ปกครองของเด็กที่มีกลุ่มอาการดาวน์ ในระหว่าง เดือนสิงหาคม พ.ศ. 2559 ถึง เดือนพฤศจิกายน พ.ศ. 2560 โดยเป็นการวัด 2 ครั้ง ครั้งแรกเมื่อเริ่มเข้าร่วม จากนั้นมีกิจกรรมกลุ่มสำหรับกลุ่มศึกษา แล้ววัดคะแนนทัศนคติอีกครั้ง ห่างกัน 6 เดือน จากครั้งแรกทั้งในทั้งกลุ่มศึกษาและกลุ่มควบคุม

ผลการศึกษา: มีผู้ปกครองเด็กที่มีกลุ่มอาการดาวน์จำนวน 35 ราย เข้าร่วมการศึกษา โดยแบ่งเป็นกลุ่มศึกษา 18 ราย และกลุ่มควบคุม 17 ราย พบว่า กลุ่มศึกษามีค่ามัธยฐานคะแนนทัศนคติดีขึ้นอย่างมีนัยสำคัญทางสถิติ ($p = 0.01$) ภายหลังการร่วมกิจกรรมกลุ่ม อย่างไรก็ตามพบว่ากลุ่มควบคุมก็มีค่ามัธยฐานคะแนนทัศนคติเพิ่มขึ้น อย่างมีนัยสำคัญทางสถิติเช่นกัน ($p = 0.02$) ส่วนค่ามัธยฐานคะแนนพัฒนาการเด็กมีความแตกต่างกันกล่าวคือ มีค่าเพิ่มขึ้นในกลุ่มศึกษาและลดลงในกลุ่มควบคุม (0.96 vs. -6.14, $p = 0.18$)

สรุป: การร่วมกิจกรรมกลุ่มของผู้ปกครองไม่ส่งผลต่อการเปลี่ยนแปลงของทัศนคติของผู้ปกครองเด็กที่มีกลุ่มอาการดาวน์ ซึ่งอาจเป็นเนื่องจากรูปแบบกิจกรรม จำนวนผู้เข้าร่วมหรือระยะเวลาของกิจกรรมกลุ่ม แต่อย่างไรก็ตามพบว่ากิจกรรมกลุ่มมีผลต่อพัฒนาการ ทำให้เด็กที่มีกลุ่มอาการดาวน์ในกลุ่มศึกษามีพัฒนาการที่ดีขึ้นกว่ากลุ่มควบคุม