SOCIODEMOGRAPHICS, DISABILITY FACTORS AND FAMILY IMPACT BETWEEN CHILDREN WITH DOWN SYNDROME AND OTHER CHILDREN WITH DISABILITIES IN KELANTAN, MALAYSIA

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Abstract— Parenting a child with disability may be a source of significant stress and affects the quality of life of the parents and families. Epidemiological evidence suggest that the impact of raising a child with disability on the parental and family functioning differ depending on the nature and severity of the children's disability. The present study was aimed to examine the sociodemographic, disability related factors, and family impact of children with Down syndrome compared with other children with disabilities (CWD). A cross-sectional study was conducted on the caregivers of children with learning disabilities in community based rehabilitation centres and schools with special education integration programme in Kelantan, Malaysia. The Malay version of PedsQL™ Family Impact Module was used to assess the family impact. Data were analysed using Independent t-test/Mann-Whitney U test and Chi-square to determine the differences between the two groups. Results show that there were significant differences between children with Down syndrome and other CWD on age, race, number of siblings, number of disabled children in the family, type of institution, and time since diagnosis. Caregivers of children with Down syndrome had significantly higher scores on Communication and Family Relationships subscales of family impact compared to caregivers of other CWD. The current study suggests that caregivers of children with Down syndrome may have better health-related quality of life and family functioning than caregivers of other CWD even though only two subscales showed statistically significant results. This study guides for future research to confirm the findings and for better planning and provision of appropriate services to the target group in Malaysia.

Index Terms—Down Syndrome, Disabilities, Health-Related Quality Of Life, Family Functioning, Family Impact

I. INTRODUCTION

Down syndrome (DS) is the most common chromosomal condition characterised by developmental disability. DS is one of the leading causes of intellectual disability, and is associated with various health problems such as heart problems, muscular dystrophy, and epilepsy or other seizure disorder [1]. Children with DS are considered children with special health care needs, which was defined as children "who have or are at increased risk for a chronic physical, developmental, behavioural, or emotional condition and who require health and related services of a type or amount beyond that required by children generally" [2].

The incidence of DS in Malaysia as reported by an earlier study was 1:959 live births [3]. Children who are diagnosed with DS are registered under 'learning disabilities (LD)' category as imposed by Malaysian Department of Social Welfare for social welfare purposes. Other conditions included under this category are global developmental delay, attention deficit hyperactive disorder (ADHD), autism, intellectual disability, slow learner, and specific LD (e.g. dyslexia, dyscalculia, dysgraphia) [4]. The Ministry of Education Malaysia recognised LD as a category of students with special needs who has learning problems in schools [5].

The birth of a child with DS or other disabilities is likely to affect the family system in many ways. In general, studies have consistently shown that parents raising a child with disability were associated with higher levels of parental stress, more symptoms of depression and anxiety, and poorer health-related quality of life (HRQoL) than in parents of typically developing children [6]-[10]. Furthermore, many studies compare parents of children with DS with those who have children with other disabilities. When compared with other children with special health care needs, children with DS had greater disease burden, faced greater unmet needs, and their families were more likely to report family impacts (e.g. financial problems and loss of employment) [1]. Yet, some authors suggest that the impact of raising a child with DS was relatively mild compared to raising children with autism and intellectual disability [7], [11]- [12].

In fact, some aspects of the impact of caregiving on the caregiver's functioning and quality of life differ depending on the nature and severity of the children's illness. Psychological problems and HRQOL were found to vary among caregivers of children with different types of developmental disability [7],[12]-

[14]. Despite the extensive knowledge of differences of family impacts in parents of children with DS and other disabilities, such research remains understudied in non-Western populations, particularly in Malaysia. Here, we use the data sample from community based rehabilitation centres and public schools with special education integration programme in one state of Peninsular Malaysia to profile the families of children with LD. We examined the differences of socioeconomic, demographics and disability related factors between children with DS and other children with disabilities (CWD). This study also was aimed to determine the family impact in the caregivers of children with DS compared with other CWD in Kelantan, Malaysia.

II. METHODOLOGY

A. Participants and Procedure

This was a cross-sectional study conducted in community-based rehabilitation (CBR) centres for the disabled people and public schools with special education integration programme in Kelantan, the most northeastern state of Peninsular Malaysia. The participants were parents or guardians (herein "caregiver") of children who identified as having LD who were registered with the Malaysian Department of Social Welfare. The inclusion criteria were as follows: (1) those who are primary caregivers; (2) have a child with the diagnosis of DS, or other types of LD such as autism spectrum disorders, ADHD, global developmental delays, intellectual disability, slow learner, or specific LD (herein "CWD"); (3) their child aged of 18 years old and below; and (4) their child lives at home. Caregivers who were absent during the study period and/or demonstrated a severe mental illness were excluded from the study.

Cluster random sampling method was employed in this study. CBR centres and schools (clusters) were randomly drawn from three regions (northern, centre, and southern) in the state of Kelantan. All eligible caregivers in the selected CBR centres and schools were then recruited into the study. Self-administered and guided questionnaires were distributed to 406 caregivers. A total of 383 (94%) returned completed questionnaires. Researchers explained the study rationale and obtained written informed consent prior to the caregivers answering the questionnaire. Structured interviewing was applied in the cases where the participants were illiterate. This study was approved by the UniversitiKebangsaan Malaysia Research Ethics Committee, the Department of Social Welfare and the Ministry of Education Malaysia.

B. Measures

A set of self-administered and guided questionnaire in Malay version which consistedof Background Information sheet and Pediatric Quality of Life Inventory™ (PedsQL™) Family Impact Module (FIM) was used as research instrument.

Background Information sheet was used to obtain socioeconomic and demographic characteristics, and disability related information of the child. Sociodemographic characteristics included child's age, gender, race, number of siblings, number of disabled children in the family, the caregiver's occupation and educational level, monthly household income, financial support received from the Department of Social Welfare or other organisations for the child and family per month, and types of institution the child attends (CBR or school). Disability related variables included time since diagnosis (duration of disability), presence of medical problems or comorbidities, types of LD, and care dependency. Care dependency was defined as the number of life domains on which the child needs care (8items - physical, mobility, eating and drinking, medication use, coping with devices/tools, entertaining, contact with other children, education). This scale ranges from 0–8, where 0 indicates the child does not need support, and score 8 indicates the child needs support on all domains [15]. The pilot study showed that this scale had good internal consistency reliability with Cronbach's $\alpha = 0.86$.

The PedsQL™ FIM [16] was used to assess the family impact in this study. This module was developed to measure the impact of pediatric chronic health conditions on parent HRQOL and family functioning. It yields three summary scores which are Total Impact Score, Parent HRQOL Summary Score and Family Functioning Summary Score. The PedsQL™ FIM Scales encompass 8 subscales: Physical Functioning, Emotional Functioning, Social Functioning, Cognitive Functioning, Communication, Worry, Daily Activities and Family Relationships. The 36 items are rated on a 5-point Likert scale with 0 = never a problem, 1 = almost never a problem, 2 = sometimes a problem, 3 = often a problem, and 4 = almost always a problem. Items are linearly transformed to a reverse-score 0-100 scale (0 = 100, 1 = 75, 2 = 50, 3 = 25, 4 = 0). Higher scores in this scale indicate better HRQOL and functioning (less negative impact). Previous study showed that the Malay version of the questionnaire had good internal consistency reliability with Cronbach's alpha values ranging from 0.73 to 0.90. Item-total correlation for all domains was acceptable, at 0.40 and above, except one item in Communication domain [17].

C. Statistical Analysis

Data analysis was conducted using IBM SPSS 22.0 (IBM Corp., USA). Descriptive analysis was used to describe sociodemographic information, disability related variables, and family impact. Results were presented as mean and standard deviation (SD) for normally distributed data. Median and inter-quartile range (IQR) were used to describe skewed data. For categorical data, results were presented as frequency and percentage (%). Statistical differences for categorical variables were conducted using Chi-

square test, and for continuous variables were using Independent t-test/Mann-Whitney U test to examine differences in socioeconomic and demographic characteristics, disability related variables and family impact scores between children with DS and other CWD. All statistical comparisons were two-sided, using $\alpha = 0.05$.

III. RESULTS

A. Sociodemographic Characteristics and Disability Related Variables of Children

The children with LD in the current study consisted of 238 (62.1%) males and 145 (37.9%) females with the mean age of 11.71 (SD = 4.29) years. Out of the 383 participants, 35.8% were children with DS. Their median monthly household income was MYR800 (IQR = MYR1000) and median monthly financial support received per month was MYR150 (IQR = MYR0). Most of the children's caregivers were unemployed (55.4%) while only 10.7% and 4.7% worked in government and private sector respectively. Of these caregivers, 84 (21.9%) had low education level (having no formal or only primary school education) and the majority of them had secondary school education (70.2%). Table 1 shows the sociodemographic profile and disability related variables of children with LD in the current study.

Table 2 compares socioeconomic, demographic and disability related variables between children with DS and other CWD. Analyses showed that there were statistically significant differences of child's age, child's race, number of siblings, number of disabled children in the family, type of institution, and time since diagnosis between children with DS and other CWD. Children with DS had lower mean age (mean = 10.48, SD = 4.80 years) compared to other CWD (mean = 12.39, SD = 3.83 years) ($p<0.001$). Mean time since diagnosis was significantly higher in children with DS (mean = 9.97, SD = 4.83 years) than other CWD (mean = 7.04, SD = 4.57 years) ($p<0.001$). There was also significant difference of type of institution between children with DS and other CWD, where only 38 children with DS in this study who came from school institution ($p<0.001$). Socioeconomic variables (i.e. monthly household income, caregiver's occupation and educational level) did not show any significant differences between children with DS and other CWD.

B. Family Impact between Children with Down Syndrome and Other CWD

Table 3 displays median, IQR and Mann-Whitney U test results on each subscale score and summary scores of the PedsQL™FIM for the DS sample group and other CWD sample group. Test of normality (Kolmogorov-Smirnov test), histogram and box and whisker plot indicated non-normal distributions of the item responses in the FIM scales for both groups. The caregivers of children with DS scored higher in Total Impact Score, Parent HRQOL Summary Score and Family Functioning Summary Score than did caregivers of other CWD, however, none of these summary scores were statistically significant. Furthermore, when we looked differences in scores for each subscale between these two groups, we found the DS sample group reported significantly higher than other CWD sample group for two subscales scores: Communication and Family Relationships subscales ($p< 0.05$).

IV. DISCUSSION

Findings on differences in demographic characteristics between children with DS and other CWD showed that child's age, child's race, number of siblings, number of disabled children in the family, and type of institution were statistically significant. Meanwhile, for disability related variables, only time since diagnosis (duration of disability) was significantly different between children with DS and other CWD. Socioeconomic variables (i.e. monthly household income, caregiver's occupation and educational level) and other disability variables did not show any significant differences between children with DS and other CWD.

Children with DS had longer duration of disability since their diagnosis (10 years) as compared than other CWD (7 years). In most cases, the diagnosis of DS was made as early as newborn according to baby's physical characteristics and results from a chromosome test administered shortly after birth [18]. Other CWD were diagnosed after one 1 year old due to the difficulty in identifying clinical features of specific diagnosis. For example, autism is usually recognised between 4 and 6 years of age, and in some cases even later. Only a small proportion of children were diagnosed before the age of 3 [7], [13]. Intellectual disability, slow learner and specific LD usually were detected earlier when they entered the primary school at age 7 years. Ideally, a child requires a multidisciplinary assessment that involves evaluation by a paediatrician, physio and occupational therapist, child psychologist or psychiatrist, etc. to confirm the diagnoses of LD.

Previous literature demonstrated that children with DS had greater number of concurrent health conditions than other children with special health care needs [1]. Nevertheless, this study found no significant association of the presence of medical problems or comorbidities and DS status. It might be resulting from problems with measuring the presence of comorbidities. The caregivers were asked whether their child had other reported medical or health problems (yes/no) rather than asking them about the presence of comorbidities with list of each specific health condition.

With regard to the family impact, past research has produced conflicting evidence as to whether parents of children who have DS experience an advantage

over parents of children who have other developmental disabilities with regard to family and parental functioning. The currentstudy findings are consistent with the idea of "Down syndrome advantage", a circumstances in which families of children with DS experience less negative impacts and higher levels of well-being than families of children with other disabilities [11], [19]. In this study, we found that caregivers of children with DS had higher scores than caregivers of other CWD for all summary scores and subscales except Cognitive Functioning subscale. However, only Communication and Family Relationships subscales showed statistically significant difference between the two groups. This indicated that caregivers of children with DS had significantly fewer problems with communicating with others and health professionals. They also had significantly fewer problems with family relationships. Although significant findings were noted for only two subscales, overall the higher scores in caregivers of children with DS implied that these caregivers had better HRQoL and family functioning than caregivers of other CWD.

Earlier local findings showed that mothers of children with DS had the lowest prevalence of psychological health problems (34%) when compared with their counterparts with autism disorder (59%) and intellectual disability (62%) [12]. On the other hand, caregivers of children with autism disorder exhibited higher scores on somatic symptoms, anxiety, social dysfunction, higher levels of stress, and lower personal well-being than did caregivers of children with DS [7], [11]-[12]. Some possible explanations for the DS advantage are that children with DS exhibit fewer behaviour problems, have better access to professional services, and parental attitude and use of coping styles [7], [11]-[12]. Another study suggests the magnitude of the DS advantage does not appear to be substantial when their study revealed differences between mothers of children with DS and mothers of children with other developmental disabilities on most maternal functioning variables disappeared after maternal age and child adaptive behaviour were controlled [20]. Corrice and Glidden (2009) also claimed that researchers who only compare DS to autism may demonstrate an "autism disadvantage" rather than a DS advantage.

The current study has certain limitations. The differences of sociodemographics, disability related variable and family impact between DS sample group and other CWD group should be interpreted with caution as the analysis was only univariate. Many important variables such as child's age and behavioural problems which affected parent and family functioning were not accounted or controlled. Despite its limitations, the current initial findings may have practical implications for future recommendations. It is interesting for future studies to look into differences of parental well-being and family functioning between parents of children with DS, parents of children with other LD and also parents of children without disability in large scale of our population. Implications for service provision aimed at families of children with more challenging behaviour problems are crucial in the context of culture.

Table 1.Sociodemographic characteristics and disability related variables of children with Down syndrome and other CWD (n=383)

Characteristics	Mean	SD	Frequency (%)
Socio-demographics			
Child's age (years)	11.71	4.29	
Child's gender			
Male			238 (62.1)
Female			145 (37.9)
Child's race			
Malay			375 (97.9)
Non-Malay			8 (2.1)
Number of siblings			
1 – 5			234 (61.1)
6 – 10			133 (34.7)
11 – 15			16 (4.2)
Number of disabled children in family			
One			337 (88.0)
Two			30 (7.8)
Three and more			16 (4.3)
Monthly household income (MYR)	800.00[a]	1000.00[b]	
Monthly financial support received (MYR)	150.00[a]	0.00[b]	
Occupation of caregiver			
Unemployed/Housewives			212 (55.4)
Private employee			18 (4.7)
Government employee			41 (10.7)
Self-employed			112 (29.2)
Highest educational level of caregiver			
No formal education			17 (4.4)
Primary school			67 (17.5)
Secondary school			269 (70.2)
University/college			30 (7.8)
Type of institution			
CBR			193 (50.4)
Schools with special education integration program			190 (49.6)
Disability related variables			
Presence of Down syndrome			
Children with Down syndrome			137 (35.8)
Other CWD			246 (64.2)
Time since diagnosis (years)	8.15	4.88	
Care dependency	20.00[a]	23.00[b]	
Presence of comorbidities			
Yes			143 (37.3)
No			240 (62.7)

[a] Median
[b] IQR

Table 2. Comparison of sociodemographic characteristics and disability related variables between children with Down syndrome and other CWD

Variables	N (%)[a]		Mean (SD)		*p* value
	Down syndrome	Other CWD	Down syndrome	Other CWD	
Child's age (years)			10.48 (4.80)	12.39 (3.83)	**<0.001**
Child's gender					
Male	77 (32.4)	161 (67.6)			0.074
Female	60 (41.4)	85 (58.6)			
Child's race					
Malay	137 (36.5)	238 (63.5)			**0.028**
Non-Malay	0 (0.0)	8 (100.0)			
Number of siblings			6 (4)[b]	4 (3)[b]	**<0.001**
Number of disabled children in family					
One	129 (38.3)	208 (61.7)			**0.006**
Two and more	8 (17.4)	38 (82.6)			
Monthly household income (MYR)			900.00 (1500.00)[b]	800.00 (700.00)[b]	0.100
Monthly financial support received (MYR)			150.00 (0.0)[b]	150.00 (0.0)[b]	0.533
Occupation of caregiver					
Unemployed/Housewives	82 (38.7)	130 (61.3)			0.186
Employed	55 (32.2)	116 (67.8)			
Highest educational level of caregiver					
Low education	37 (44.0)	47 (56.0)			
Secondary education	87 (32.3)	182 (67.7)			0.099
Higher education	13 (43.3)	17 (56.7)			
Type of institution					
CBR	99 (51.3)	94 (48.7)			**<0.001**
School	38 (20.0)	152 (80.0)			
Time since diagnosis (years)			9.97 (4.83)	7.04 (4.57)	**<0.001**
Care dependency			24.00 (21.00)[b]	17.00 (25.00)[b]	0.054
Presence of comorbidities					
Yes	51 (35.7)	92 (64.3)			0.973
No	86 (35.8)	154 (64.2)			

[a] Rows total to 100%
[b] Median (IQR), Mann Whitney U test applied

Table 3. Subscale scores of the PedsQL™ Family Impact Module in caregivers of children with Down syndrome and caregivers of other CWD

Scale	Down syndrome (n=137)	Other CWD (n=246)	*Z*	*p* value
	Median (IQR)	Median (IQR)		
Total Impact Score	80.56 (19.44)	78.47 (21.70)	-1.327	0.185
Parent HRQOL Summary Score	78.75 (23.13)	77.50 (25.00)	-0.631	0.528
Physical Functioning	79.17 (25.00)	75.00 (33.33)	-0.362	0.717
Emotional Functioning	80.00 (30.00)	75.00 (35.00)	-1.468	0.142
Social Functioning	93.75 (25.00)	84.38 (31.25)	-1.844	0.065
Cognitive Functioning	75.00 (30.00)	80.00 (35.00)	-0.908	0.364
Communication	91.67 (25.00)	83.33 (33.33)	-2.395	**0.017**
Worry	80.00 (25.00)	75.00 (25.00)	-0.368	0.713
Family Functioning Summary Score	87.50 (18.75)	81.25 (25.00)	-1.919	0.055
Daily Activities	75.00 (29.17)	75.00 (35.42)	-0.454	0.650
Family Relationships	90.00 (20.00)	85.00 (30.00)	-2.504	**0.012**

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