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ORIGINAL ARTICLE

Family Burden of Intellectually Disabled Children with Challenging Behaviour

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ABSTRAK

Tingkah laku yang mencabar dalam kalangan kanak-kanak dan remaja kurang upaya intelektual memberikan cabaran besar dalam proses penjagaan. Beban keluarga adalah tinggi, namun jarang diberi penekanan dalam pengurusan. Oleh itu, kajian keratan rentas ini bertujuan untuk menilai tingkah laku mencabar dalam kalangan kanak-kanak dan remaja kurang upaya intelektual, beban keluarga serta faktor-faktor yang berkaitan dalam kalangan penjaga mereka. Seramai 88 penjaga kepada kanak-kanak dan remaja yang menghadiri Unit Psikiatri Kanak-Kanak dan Remaja, Hospital Canselor Tuanku Muhriz telah mengambil bahagian dalam kajian ini. Faktor sosio-demografi dan tingkah laku mencabar kanak-kanak dan remaja dinilai menggunakan soal selidik sosio-demografi dan 'Developmental Behaviour Checklist'. Beban keluarga pula dinilai menggunakan 'Burden of Family Interview Schedule'. Sebanyak 52% kanak-kanak dan remaja dilaporkan mempunyai tingkah laku mencabar, manakala beban keluarga dilaporkan dalam kalangan 76% penjaga. Skor purata keseluruhan beban keluarga adalah jauh lebih tinggi dalam kalangan kanak-kanak dan remaja dengan tingkah laku mencabar berbanding dengan mereka yang tidak menunjukkan tingkah laku mencabar (19.02 vs 4.93, P < 0.001). Tingkah laku menyendiri (self-absorbed behaviour) (B: 0.313, 95% CI: 0.222 - 0.404), tempoh waktu berinteraksi (duration of contact hours) (B: 0.197, 95% CI: 0.074 - 0.320) dan preskripsi ubat psikotropik (B: 6.474, 95% CI: 1.400 - 11.548) merupakan peramal signifikan terhadap beban keluarga dalam sampel ini. Hasil kajian mendapati beban keluarga yang tinggi dalam kalangan penjaga kanak-kanak dan remaja kurang upaya intelektual menjadi lebih berat dengan penglibatan tingkah laku yang mencabar. Oleh itu, beban keluarga perlu sentiasa dipertimbangkan dalam penilaian dan pengurusan menyeluruh kanak-kanak dan remaja yang mempunyai kurang upaya intelektual.

***Kata kunci:** Keletihan mental; kurang upaya intelektual; masalah tingkah laku; penjaga keluarga; stres*

ABSTRACT

Challenging behaviours in children and adolescents with intellectual disability imposes a great challenge in the care-giving process. Family burden is high but it is not commonly focused on the management. Hence, this cross-sectional study aimed to assess challenging behaviours among the intellectually

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disabled children and adolescents, family burden and its associated factors among their caregivers. A convenient sample of 88 caregivers of children and adolescents attending the Child and Adolescent Psychiatry Unit, Hospital Canselor Tuanku Muhriz participated in the study. Socio-demographic factors and challenging behaviours of the children and adolescents were assessed using a socio-demographic questionnaire and Developmental Behaviour Checklist respectively. Family burden was assessed using Burden of Family Interview Schedule. A total of 52% of the children and adolescents were reported to have challenging behaviours while family burden was reported in 76% of the caregivers. Mean total score of family burden was significantly higher in children and adolescents with challenging behaviours compared to those without challenging behaviours (19.02 vs 4.93, $p < 0.001$). Self-absorbed behaviours (B: 0.313, 95% CI: 0.222 - 0.404), duration of contact hours (B: 0.197, 95% CI: 0.074 - 0.320) and prescription of psychotropic medications (B: 6.474, 95% CI: 1.400 – 11.548) were significant predictors of family burden in our sample. Family burden is high among caregivers of intellectually disabled children and adolescents, with significantly higher levels of burden reported in the presence of challenging behaviours. Hence, family burden should always be considered in the comprehensive assessment and management of children and adolescents with intellectual disability.

Keywords: Behavioural problems; burnout; family caregivers; intellectual disability; stress

INTRODUCTION

Challenging behaviour is defined as 'culturally abnormal behaviour or behaviours of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community services (Emerson et al. 2001). It is common among the intellectually disabled children and adolescents with prevalence ranging from 10% to 15% (Dworschak et al. 2016; Emerson et al. 2001; National Institute for Health and Care Excellence 2015). Among the commonly seen challenging behaviour are self-injurious behaviour, aggression to others, inappropriate sexual behaviour and stereotype behaviour (Royal College of Psychiatrists 2007). Many factors including physical factors such as pain and the need for sensory stimulation and psychological factors such as feeling lonely, boredom, isolated and communication problem may possibly contribute to challenging behaviour among the intellectually disabled children (De Winter et al. 2011).

The presence of challenging behaviour jeopardises the physical and mental health of caregivers, and has been associated with increased burden and stress among caregivers (Dawson et al. 2016; Isa et al. 2017; Mcconnell & Savage 2015; Rose et al. 2016). It is a strong predictor of increased burden among parents who care for their children with intellectual disability because of the increased difficulties in the care-giving process (Maes et al. 2003; Nachshen et al. 2005; Turan Gürhopur & Dalgıç 2017). There is a higher risk of physical injuries when challenging behaviour involves aggression while socially deviant behaviour and communication difficulties may lead to stigmatisation, social rejection and discrimination (Jones et al. 2007; Royal College of Psychiatrists 2007). The presence of challenging behaviour may lead to hospitalisation and institutionalisation adding further burden to the caregivers (Emerson et al. 1999; Perry et al. 2007).

Family burden is of significant importance because it may lead to mental health problems such as depression and anxiety among the caregivers (Bhatia et al. 2015). Understanding family burden among caregivers of children and adolescents with intellectual disability in the local context will facilitate the provision of services and support needed.

Studies on challenging behaviour and family burden in developing countries like Malaysia are scarce and most of our knowledge on this area is based on studies done in developed countries (Emerson 2011). There is a gap in the understanding given the different socio-cultural context between the different countries (Allison & Strydom 2009; Parmenter 2008). In developing countries like Malaysia, where the support services to children and adolescents with intellectual disability are still limited, the burden experienced by the caregivers is predictably increased. A United Nations Children's Fund (UNICEF) study in Malaysia reported a greater stigma attached to the mentally and intellectually disabled children compared to those with physical disability. Culturally, it is believed that mothers should behave properly during pregnancy. In the local cultural context, it is important to avoid cultural taboos during pregnancy to ensure a birth of a normal child. Therefore, mothers have tendency to blame themselves or be blamed by others for their children's disability, leading to increased stigma, poor acceptance and more social isolation (United Nations Children's Fund Malaysia 2017).

Hence, this study aimed to assess the rate of challenging behaviour among children and adolescents with intellectual disability, family burden and associated factors among their caregivers. The findings of this research provided valuable insights into the problems faced, while taking local cultural factors in Malaysia into account. This understanding illuminated issues unique to the country and other developing nations, directly addressing the existing research gap. Additionally, it facilitated the identification of specific needs for improving current services and interventions, as well as the development of new facilities and services. By understanding the family burden within the local cultural context, clinicians will be better equipped to implement more appropriate support for children and their families.

MATERIALS AND METHODS

This was a cross-sectional study assessing family burden in relation to challenging behaviour among caregivers of intellectually disabled children and adolescents, attending Child and Adolescent Psychiatry Unit, Hospital Canselor Tuanku Muhriz (HCTM). Children aged between 4 to 18 years, with a clinical diagnosis of intellectual disability diagnosed by paediatrician or psychiatrist, based on diagnostic criteria of Diagnostic Statistical Manual IV-TR (DSM IV-TR) or International Classification of Disease 10 (ICD-10), and cared by caregivers in the family context were included to participate in the study (American Psychiatric Association 2000; World Health Organization 2016). Inclusion criteria for caregivers were aged 18 years and above, provided unpaid care in the past 12 months, fluent in Malay, English or Mandarin and consented to participate in the study.

Caregivers were conveniently selected and assessed for socio-demographic data and challenging behaviour using a self-reported socio-demographic questionnaire and Developmental Behaviour Checklist (DBC), respectively. Caregivers were later interviewed by the first author to assess for family burden using Burden of Family Interview Schedule (BFIS).

Developmental Behaviour Checklist

DBC-P is a caregiver self-reported 96-item instrument to assess behavioural and emotional problems among young people with intellectual disability (Einfeld et al. 2002). A Total Behaviour Problem Score (TBPS) of 46 or above was considered a major behavioural or emotional problem. Since DBC-P was not validated in the local setting, we carried out an analysis to determine the internal reliability of DBC-P in our sample. The results showed good internal reliability with Cronbach Alpha of 0.832.

Burden of Family Interview Schedule

On the other hand, BFIS is a 24-item semi-structured interview schedule assessing family burden in various areas including financial, family routine, family leisure, family interaction, physical and mental health of family members (Pai & Kapur 1981). Total score is calculated by summation of the 23 items (excluding the question regarding loss of patient's income in the Financial Burden section which is not applicable in this study). The minimum score is 0 and the maximum score is 69 whereby a higher score reflects a higher level of burden.

Data collected were entered and analysed using the Statistical Package for Social Science (SPSS) version 20 (IBM Corp., Armonk, USA). Socio-demographic information, challenging behaviour among children/adolescents and severity of family burden were assessed using descriptive analysis. Continuous data were expressed in median and interquartile range (IQR) while categorical data were in frequency and percentage. Independent t-test was used to compare the burden score between caregivers of patients with challenging behaviour and those without challenging behaviour. Multiple linear regression analysis using a stepwise approach was performed to identify independent predictors of family burden. Statistically significant level was set at $p < 0.05$.

The study was approved by the Research Ethics Committee of Universiti Kebangsaan Malaysia (FF-2014-352) and registered in the National Medical Research Registration website. Consent was obtained from the participants and confidentiality was assured.

RESULTS

A total of 103 caregivers were conveniently recruited but 15 caregivers were excluded for various reasons including exceeding children/adolescents' age (6), staying in the nursing home (1), uncooperative children/adolescents (2) and incomplete interview (6).

Socio-demographic profiles of 88 caregivers and their children were summarised in Table 1. Most of the caregivers were mothers (71.6%), aged 38-47 (47.7%), with family earning less than RM5000 per month (75%), and had spent four days or more (> 96 hours) in a week with their children (98.9%). Children and adolescents were mainly males (68%), with a median age of 14 years, and having high comorbid psychiatric illness (64%) (Table 2).

Of the 88 participating children and adolescents, 52% (n=46) had clinically significant challenging behaviour, with TBPS in DBC-P of 46 or more. The median of TBPS was 47 with an interquartile range of 38.5. Among all the DBC-P

TABLE 1: Socio-demographic profile of caregivers

Socio-demographic Profile of Caregivers	n (%)	Median (IQR)
Age		
18-27	3 (3.4)	-
28-37	11 (12.5)	
38-47	42 (47.7)	
48-57	26 (29.5)	
58-67	3 (3.4)	
68-77	2 (2.3)	
78 or above	1 (1.1)	
Gender		
Male	25 (28.4)	-
Female	63 (71.6)	
Ethnic		
Malay	49 (55.7)	-
Chinese	37 (42.0)	
Indian	2 (2.3)	
Highest education level		
Primary education	6 (6.8)	-
Secondary education	59 (67.0)	
Tertiary education	23 (26.2)	

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Socio-demographic Profile of Caregivers	n (%)	Median (IQR)
Occupation		
Employed full time	49 (55.7)	-
Employed part time	5 (5.7)	
Unemployed	34 (38.6)	
Marital status		
Married	79 (89.8)	-
Single/Divorced	9 (10.2)	
Relationship with patient		
Father	19 (21.6)	-
Mother	63 (71.6)	
Siblings	2 (2.3)	
Grandparents	3 (3.4)	
Others	1 (1.1)	
Household Income (RM)	25 (28.4)	-
2,500 or less	42 (47.7)	
2,501 to 5,000	7 (8.0)	
5,001 to 7,500	9 (10.2)	
7,501 to 10,000	5 (5.7)	
10,001 or more		
Number of households, including patient	-	5 (2.00)
Years of care-giving		13.5 (6.75)
Duration of weekly contact (in days)		
4 days or less	1 (1.1)	
More than 4 days	87 (98.9)	

TABLE 2: Socio-demographic and clinical profile of children and adolescents with intellectual disability

Socio-demographic and Clinical Profile of Children and Adolescents with Intellectual Disability	n (%)	Median (IQR)
Age, years		14.0 (6.00)
Gender		
Male	60 (68.8)	
Female	28 (31.2)	
Ethnic		
Malay	49 (55.7)	
Chinese	36 (40.9)	
Indian	2 (2.3)	
Japanese	1 (1.1)	
Education level		
Preschool	8 (9.1)	
Inclusive class	20 (22.7)	
Special school	48 (54.5)	
Integrated class	12 (13.6)	
Number of patient(s) who has comorbid psychiatry illness	57 (64.8)	
Autism	12(13.6)	
Attention and hyperactivity disorder (ADHD)	29 (33.0)	
Autism and ADHD	10 (11.4)	
Psychosis	6 (6.8)	

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Socio-demographic and Clinical Profile of Children and Adolescents with Intellectual Disability	**n (%)**	**Median (IQR)**
Number of patient(s) who has comorbid medical illness	23 (26.1)	
Genetic syndrome	5 (5.7)	
Epilepsy	7 (8.0)	
Congenital heart disease	1 (1.1)	
Bronchial asthma	3 (3.4)	
Eye disorder	3 (3.4)	
Cerebral palsy	3 (3.4)	
Hormonal disorder	1(1.1)	
Specific Intervention		
Medication	27 (30.7)	
Psychological intervention	2 (2.3)	
Occupational therapy	10 (11.4)	
Speech therapy	3 (3.4)	
Others	5 (5.7)	
Combination of any above	24 (27.3)	
Usual follow-up	17 (19.3)	
Number of patient(s) who required hospitalisation due to challenging behaviour	1 (1.1)	

subscales, the highest level of disturbances was observed in anxiety subscale (76 percentile), followed by social-relating subscale (74 percentile), communication disturbance subscale (66 percentile), disruptive/antisocial subscale (60 percentile) and self-absorbed subscale (46 percentile) (Figure 1).

Table 3 showed categories and severity of family burden reported by the caregivers. The level of burden was based on Item G – Subjective Burden which was scored on Likert Scale of 0-3 (0 = no burden; 1= mild burden; 2 = moderate burden; 3 = severe burden). A total of 71.6% of caregivers reported burden in caring for the intellectually disabled patients ranging from mild burden (33%), moderate burden (22.7%) and severe burden (15.9%), whereas only 28.4% reported no burden (Item G). Areas that were commonly related to family burden include not going to work, school, college etc. (Item B1), effects on household atmosphere (Item D1), arguments, quarrels, assaults (Item D2) and psychological impact untreated (Item F2). Highest proportion of caregivers reported some form of burden when the challenging behaviour affected the household environment (Item D1) (59%) and psychological impact of the challenging behaviour were not treated (Item F2) (51%). In fact, about 20% caregivers had severe burden in these two areas as well, which was the highest compared to other items. Structural damage in the family, Item D5 (6.8%) and emotional problems requiring treatment, item F1 (9.1%) were reported by fewer caregivers, respectively.

Comparison of caregivers' burden of children and adolescents who have intellectual disability with challenging behaviour and without challenging behaviour was shown in Table 4. Caregivers who took care of children and adolescents, having intellectual disability and challenging behaviour had significantly higher levels of burden (mean total family burden score = 19.02, $p<0.001$) compared to those without challenging behaviour (mean total family burden score = 4.93).

Children and adolescents' age, gender, education level, types of intervention received, severity of challenging behaviour (across all five subscales), duration of care-giving and weekly contact hours showed statistically significant association with family burden (Table 5). However, only three factors; self-absorbed

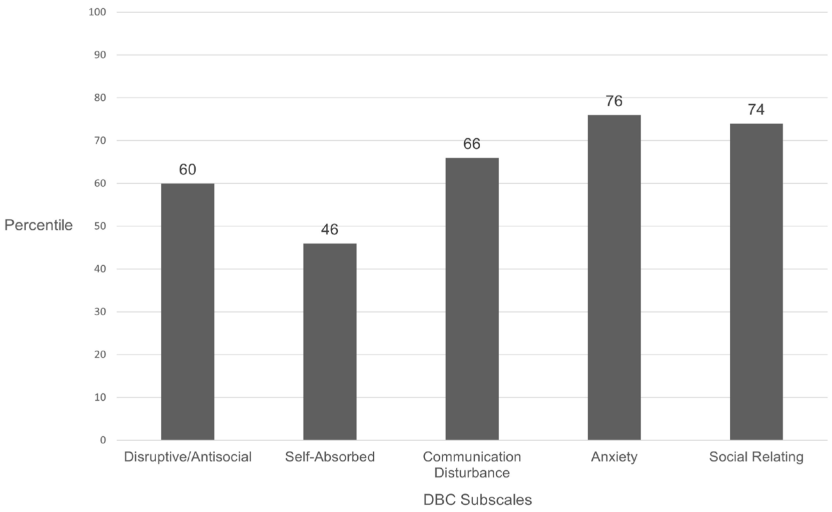

FIGURE 1: Types of challenging behaviours among children and adolescents with intellectual disability

TABLE 3: Categories and severity of family burden among caregivers

Category of Burden	**Number of Caregivers (%)/ Severity**			
	Nil (0)	**Mild (1)**	**Moderate (2)**	**Severe (3)**
A. Financial burden				
1. Loss of patient's income	NR	NR	NR	NR
2. Loss of income of any other member of the family due to patient's illness	70(79.5)	6(6.8)	7(8.0)	5(5.7)
3. Expenditure incurred due to patient's illness and treatment	54(61.4)	10(11.4)	13(14.8)	11(12.5)
4. Expenditure incurred due to extra arrangements	75(85.2)	4(4.5)	6(6.8)	3(3.4)
5. Loans taken or saving spent	71(80.7)	4(4.5)	7(8.0)	6(6.8)
6. Any other planned activity put off because of the patient's illness	69(78.4)	6(6.8)	8(9.1)	5(5.7)
B. Disruption of routine family activities				
1. Patient not going to work, school, college, etc	48(54.5)	22(25.0)	9(10.2)	9(10.2)
2. Patient not helping in the household work	63(71.6)	16(18.2)	6(6.8)	3(3.4)
3. Disruption of activities of other members of the family	57(64.8)	15(17.0)	4(4.5)	12(13.6)
4. Patient's behaviour disrupting activities	59(67.0)	11(12.5)	10(11.4)	8(9.1)
5. Neglect of the rest of the family due to patient's illness	61(69.3)	11(12.5)	8(9.1)	8(9.1)
C. Disruption of family leisure				
1. Stopping of normal recreational activities	57(64.8)	15(17.0)	5(5.7)	11(12.5)
2. Patient's illness using up another person's holiday and leisure time	64(72.7)	9(10.2)	4(4.5)	11(12.5)
3. Patient's lack of attention to other members of the family, such as children, and its affect on them	70(79.5)	6(6.8)	4(4.5)	8(9.1)
4. Abandoning leisure activity	70(79.5)	4(4.5)	7(8.0)	7(8.0)

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Category of Burden	**Number of Caregivers (%)/ Severity**			
	Nil (0)	**Mild (1)**	**Moderate (2)**	**Severe (3)**
D. Disruptions of family interaction				
1. Ill effects on household atmosphere	36(40.9)	21(23.9)	13(14.8)	18(20.5)
2.Arguments, quarrels, assaults	42(47.7)	29(33.0)	11(12.5)	6(6.8)
3. Social isolation	74(84.1)	7(8.0)	4(4.5)	3(3.4)
4. Social introversion	70(79.5)	8(9.1)	3(3.4)	7(8.0)
5. Structural damage	82(93.2)	3(3.4)	0	3(3.4)
F. Effect on mental health of others				
1. Emotional problems requiring treatment	80(90.9)	3(3.4)	4(4.5)	1(1.1)
2. Psychological impact untreated	43(48.9)	16(18.2)	12(13.6)	17(19.3)
G. Subjective burden	25(28.4)	29(33.0)	20(22.7)	14(15.9)
H. Global burden	25(28.4)	26(29.5)	20(22.7)	17(19.3)

NR: not related

TABLE 4: Independent t-test of caregivers' burden of children and adolescents who have intellectual disability with challenging behaviour and without challenging behaviour

Category of family burden	**Number of caregivers of patients having ID and CB (n = 46)**	**Number of caregivers of patients having ID without CB (n = 42)**	**p value**
Mean total family burden score	19.02	4.93	<0.001*

ID: intellectual disability; CB: challenging behaviour

TABLE 5: Factors associated with family burden

Variables	**Crude B**	**95% CI[a]**	**Adjusted B**	**95% CI[b]**
Children/Adolescents				
Age	0.874	0.090-1.658	-	
Gender	6.510	.072-12.947	-	
Education Level				
Normal School	-6.659	-13.839-0.521	-	
Special School	8.242	2.339-14.144	-	
Integrated Program	-6.421	-15.254-2.412	-	
Specific Intervention				
Medications	10.741	4.500-16.982	6.474	1.400-11.548
Psychological Intervention	-4.907	-25.465-15.652	-	
Occupational Therapy	-10.826	-20.210-1.442	-	
Speech Therapy	-5.482	-22.348-11.383	-	
Other Treatment	1.595	-11.653-14.843	-	
Combination of Any Above	2.802	-4.060-9.664	-	
Caregivers				
Duration of Care	0.763	0.094-1.431	-	0.074-0.320
Weekly Contact Hours	0.260	0.112-0.408	0.197	

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Variables	Crude B	95% CI^a	Adjusted B	95% CI^b
Challenging Behaviour				
Disruptive/Antisocial Subscale	0.282	0.159-0.406	-	
Self-Absorbed Subscale	0.313	0.222-0.404	0.313	0.222-0.404
Communication Disturbance Subscale	0.132	0.017-0.248	-	
Anxiety Subscale	0.190	0.074-0.305	-	
Social Relating Subscale	0.237	0.124-0.350	-	

^{a}Simple Linear Regression
^{b}Multiple Linear Regression (Stepwise Approach), adjusted R^2 = 44%

subscale (B: 0.313, 95% CI: 0.222 - 0.404), weekly contact hours (B: 0.197, 95% CI: 0.074 - 0.320) and children' specific intervention i.e. medication(s) (B: 6.474, 95% CI: 1.400 - 11.548) remained as significant predictors of family burden after the analysis of multiple linear regression (Table 5). These three factors explained 44% of the variance.

DISCUSSION

About half of the children and adolescents in this study were reported to have significant challenging behaviour. In keeping with previous studies, majority of caregivers (76%) in our sample had high level of family burden with significantly higher level of burden reported in the presence of a challenging behaviour (Al-Krenawi et al. 2011; Oshodi et al. 2014; Turan Gürhopur & Dalgıç 2017).

Presence of challenging behaviour is a strong predictor of increased burden among parents who cared for their children with intellectual disability, as found in several studies (Irazábal et al. 2012; Maes et al. 2003; Nachshen et al. 2005). This is not surprising given the specific needs of the care-giving process that is proven to be physically and mentally challenging for caregivers. In line with previous findings, we found higher disturbances in household atmosphere and untreated psychological impact of family burden compared to other aspects of family burden (Kaur & Arora 2010; Morya et al. 2015; Turan Gürhopur & Dalgıç 2017). Resilience among parents of children with intellectual disabilities is lower than the general population, and poor familial relationship is an important contributing factor (Gerstein et al. 2009; Peer & Hillman 2014; Wong et al. 2015). Hence, disturbance in household atmosphere will interrupt family interaction, lower family resilience and increase family burden. Untreated psychological impact of family burden will further increase family burden.

Self-absorbed behaviour, duration of contact hours and prescription of psychotropic medications in children and adolescents with intellectual disability were found to be significant predictors of family burden in our sample. Self-absorbed subscale contains items of aggression and social deviant, that may possibly cause stigma, shame and social rejection leading to increased burden among caregivers (Maes et al. 2003; Ngo et al. 2012; Turan Gürhopur & Dalgıç 2017). In addition, aggression is also physically and mentally challenging for families, contributing further to family burden (Van Berkum & Haveman 1995). Prolonged contact hours may signify higher exposure to challenging behaviour and lesser respite period, leading to increased family burden among caregivers of individuals with intellectual disability (Souza et al. 2017). Prescription of psychotropic medications predicts family burden in our study which is probably mediated by the presence of challenging behaviour. Since behavioural intervention is usually the first line management, the use of psychotropic medications may imply severity of behaviour requiring pharmacological management. Despite questionable efficacies, medications are commonly given to intellectually disabled children with challenging behaviour as a form of behaviour restraint, particularly when behaviour management alone fails to treat the problem (Brylewski & Duggan 2004; Tsiouris 2010). Family burden is of important significance not only because it is associated with psychiatric illnesses but has also been shown to be the strongest predictor of psychiatric illnesses among caregivers of individuals with intellectual disability (Bhatia et al. 2015; Gallagher et al. 2008). However, we did not control for confounders such as comorbid psychiatric illnesses that were found to be high in our sample. The family burden may be directly caused by the psychiatric illnesses rather than challenging behaviour. Nevertheless, it implies the importance of preventing or controlling family burden before it triggers development of psychiatric illnesses.

From the cultural perspective, Malaysian women, particularly Malays, are still expected to take responsibilities of the families in keeping with the traditional role of raising children (Abdullah et al. 2008). This is one possible reason for the significantly higher number of women as caregivers in this study. Furthermore, mothers as compared to fathers were more negative in appraising the impact of having intellectually disabled children, leading to high level of burden among them (Luijkx et al. 2019). The presence of challenging behaviour enhances stigma and social isolation among caregivers possibly because of the nature and visibility of the behavioural problem (Ngo et al. 2012; Raghavan & Small 2004). In the local context, caregivers particularly mothers are more vulnerable given the cultural tendency to blame mothers for their children's disability (United Nations Children's Fund Malaysia 2017).

These findings provide new insight to our understanding of challenging behaviour and family burden among caregivers of children and adolescents with intellectual disability in the local context although comparison is difficult because local studies are lacking. Nevertheless, family burden among caregivers of intellectually disabled children and adolescents needs to be taken more seriously. Behaviour management is no doubt important to prevent and minimise challenging behaviour, particularly self-absorbed behaviour among the children and adolescents, but similar focus should be given on their caregivers. Although clinical services in the government hospitals are heavy, assessment of family burden and psychiatric illnesses among caregivers should not be neglected. Intervention programmes and support groups, particularly in the public hospitals, should be increased and made accessible to cater for the specific needs of these children and their families. Intervention programmes will provide the respite needed by families from time to time. In contrast to previous findings, our study did not find factors such as age and gender of the caregivers, presence of comorbid psychiatric and medical conditions to be significant predictors of family burden (Bhatia et al. 2015; De Winter et al. 2011; Irazábal et al. 2012).

These may be explained by the limitations of the study requiring a cautious interpretation of the findings. Firstly, small sample size and convenient sampling may reduce the power of the study to detect associations with family burden. Confounding factors such as comorbid psychiatric illnesses were not controlled. Secondly, most of the children and adolescents received clinical diagnosis without proper psychological assessment, as required by DSM IV-TR. Furthermore, the use of the DSM-IV-TR, which has been replaced by the new classification, DSM-5, may influence diagnoses and affect inclusion criteria of the study. Thirdly, socio-cultural factors should be given more emphasis given the important role in perceived family burden in the local setting. Finally, the findings may not be generalised to other settings because the study was conducted in a specific setting of a tertiary hospital in an urban area of Kuala Lumpur.

Future research should address current limitations by utilising larger size, randomised sample to enhance the statistical power of the study. It is crucial to control for confounding factors, such as comorbid psychiatric illnesses, to accurately isolate the effects of family burden. Additionally, comprehensive psychological assessments should be conducted in line with DSM-5 guidelines to improve diagnosis accuracy and reliability. Emphasising socio-cultural factors through qualitative approaches can provide deeper insights into their role in perceived family burden. To enhance generalisability, multi-site studies across different geographical and socio-economic contexts are recommended. Lastly, longitudinal studies can track changes over time, offering insights into the long-term causal effects of challenging behaviour and family burden.

CONCLUSION

In conclusion, the presence of challenging behaviour in children with intellectual disability is associated with increased burden among their caregivers. Self-absorbed behaviour and prolonged contact hours as well as prescription of psychotropic medications to children and adolescents are significant predictors of family burden among caregivers. To effectively address caregiver burden, healthcare systems should implement routine assessments during clinical visits to identify specific challenges faced by caregivers. Establishing support programs that offer respite care will allow caregivers to take necessary breaks and prevent burnout. Educational workshops and support groups can equip caregivers with effective strategies for managing difficult behaviours while fostering community connections. Integrating multidisciplinary teams, including mental health professionals and social workers, will ensure comprehensive support for both children and their caregivers. Additionally, advocacy for increased funding and resources dedicated to family support is essential. By taking these steps, healthcare systems can alleviate caregiver burden and improve outcomes for children and their families.

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