

Cost Analysis of Constipation Management in Children with Disabilities from Caregivers' Perspective: Preliminary Findings

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ABSTRACT

Background: Children with disabilities frequently experience comorbidities, with constipation being one of the most prevalent. This condition is often linked to neurological and disability conditions in such children. Managing constipation can impose significant financial burdens in term of direct medical and non-medical costs on caregivers, but data on the associated costs are limited. This study aimed to estimate the medical and non-medical expenses of caregivers of children with disabilities in managing constipation during the 2019 financial year.

Methods: A cross-sectional quantitative survey was conducted to assess the costs incurred by caregivers of children with disabilities who experienced constipation. 68 caregivers from Pahang were recruited through purposive sampling. A self-administered costing questionnaire was used to capture medical and non-medical expenses data.

Results: The findings revealed that the mean age of children was 10.82 ± 3.204 , 29% of the children had intellectual disabilities, 41.2% experienced constipation for less than six months, and the majority had mild constipation. The median cost attended the CBR programme was RM1,040.00 (554.84), Government hospitals RM 344.40 (138.72), private hospitals RM 1,255.80 (657.72) and alternative rehabilitation for constipation was RM 1,147.20 (701.93). The Median caregiver's medication and supplements cost was RM890.80 (384.25). The findings show that, lowest cost spent for government facilities compared to private and alternative facilities because high subsidiaries provided by Malaysia government.

Conclusion: The study highlights that caregivers of children with disabilities who were facing constipation tend to prefer non-medical treatments over medical interventions, leading to higher non-medical costs. These findings revealed that parents prefer to non-medical rehabilitation due to accessibility, cultural preference and affordable.

Keywords: Constipation; Children with disabilities; Medical costs; Non-medical costs

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INTRODUCTION

Chronic constipation is a common and heterogeneous disorder, which is often characterised by difficult, infrequent stool passage or incomplete evacuation. The definition of constipation in healthy children, as recently proposed by experts in paediatric gastroenterology, includes 'large-diameter stools that may obstruct the toilet, withholding behaviour, and 'no evidence of structural disease'. In addition, faecal incontinence as a symptom of constipation is difficult to detect as it could be due to a lack of toilet training. Constipation is a common problem among children with disabilities. Most children with severe disabilities need to use nappies, and faecal incontinence as part of a definition of constipation cannot be extrapolated to children with neurological impairment.

Population-based studies have estimated that the prevalence of chronic constipation in North America varies between 2% and 27% of children and adults, leading to at least 2.5 million physician visits annually in the United States (1). However, scarce data on the prevalence of constipation among children with disabilities in Malaysia setting.

Chronic constipation is a common problem in children with disabilities. Contributory factors include inactivity, severe skeletal deformity, extensor spasm, and decreased muscle tone (e.g. in Down syndrome); insufficient fluid intake may also predispose to constipation, especially for those who tend to choke, dribble or vomit. In addition, for those with masticatory and swallowing problems, their pureed diet may be insufficient to stimulate active peristalsis in the bowel. Furthermore, children with pontine lesions were known to have colonic and anorectal dysfunction. Constipation is not merely a minor problem causing abdominal discomfort or vomiting. It has been observed that the increased frequency of convulsions in epileptic children may be related to constipation, probably because of the associated stress (2). Moreover, signs and symptoms of ventriculoperitoneal shunt dysfunction may develop because of constipation (2,3). Anatomical and muscle motility abnormalities such as megarectum or megacolon can arise due to chronic constipation.

Constipation is often a relapsing chronic condition; children may repeatedly present for constipation for a prolonged time, which may increase the cost of managing this health problem

(4) due to increasing medical and non-medical treatment. In a recent study conducted by Hasan et al. (2019), parents' and caregivers' costs for medical treatment and alternative treatment for their children with disabilities found that costs spent were median of RM 1,320.00 (1,978.00) and RM 6,726.36 (7,987.00) per child, respectively (5). Although all Malaysian citizens received subsidies from the government, most parents and caregivers were still looking for alternative treatment that incurred costs and contributed to the family's economic burden. Although costs of managing constipation for children with disabilities are thought to be high from both medical costs and non-medical costs to date, there have been no studies exploring estimating costs incurred by caregivers (6), especially in the Malaysian setting. Thus, this study aimed to assess the medical costs and non-medical costs incurred by caregivers in managing constipation for their children with disabilities.

Table 1: Rome III diagnosis criteria for functional constipation (16)

Must include two or more of the following:

- Straining*
- Lumpy or hard stools*
- Sensation of incomplete evacuation*
- Sensation of anorectal obstruction or blockage*
- Manual maneuvers to facilitate defecation (eg: digital evacuation, support of the pelvic floor) * < 3 defecation/week

Loose stool rarely present without the use of laxatives

Insufficient criteria for irritable bowel syndrome with constipation

*Symptoms must be present for more than 3 months (>3 months), with onset >6 months before diagnosis. *Present in >25% of defecations.*

METHODS

Study Design

A cost analysis and cross-sectional study was performed.

Study Setting

This study was conducted at the Community-Based Rehabilitation Centre (CBR) in Pahang from October 2020 until January 2021 to estimate the costs incurred by caregivers in managing constipation problems for their children with disabilities. The study samples were recruited from CBR centres in Pahang and due to small sample size, the researcher decided to analyse the data as a for preliminary study finding.

Population and Sample Size

This study employed purposive sampling method. All participants who met the inclusion and exclusion criteria were recruited. From the total population size, the sample size was calculated using Raosoft, a sample size calculator with a margin of error of 5%, a confidence level of 95%, a population size of 360, a response distribution of 50%, and a suggested sample size of 187. However, due to the Movement Control Order during COVID-19 pandemic, sample were recruited in Kuantan setting and only 68 caregivers of children with disabilities could participate in the study.

Eligibility Criteria

Inclusion criteria: Children with disabilities aged 0 to 18 who participated in the CBR programme and experienced constipation more than 6 months and caregivers who consented and were willing to participate were included.

Exclusion criteria: Children with disabilities over 18 were absent during data collection and unwilling to participate in the study.

Instruments

This study used a modified self-administered questionnaire on constipation from Bhandari and Shahi (2019) and a costing analysis questionnaire adopted from Hasan et al. (2019) (5,6). Therefore, the questionnaire was translated into Malay using the forward and backward translation method.

This questionnaire consisted of three parts: Part A, socio-demographics information of children with disabilities, including gender, age, ethnic, type of disabilities, duration of experiencing constipation and the severity of constipation. Part B, socio-demographics information of caregivers, including age, ethnic, education levels, occupation, monthly income and source of income. Part C included direct and indirect medical and non-medical costs incurred in managing the constipation of their children with disabilities, such as the cost of attending CBR programmes, government and private rehabilitation, and alternative rehabilitation (such as traditional massage). One-year expenditures related to direct and indirect medical and non-medical costs in the 2019 institutional year were estimated using the Activity-Based Costing (ABC) approach (5).

Data Collection

The questionnaire was distributed through email after obtaining approval from the ethical committee. After receiving permission from CBR supervisors, the researcher explained the briefing about the study objectives, the significance of the research, and how to answer the questionnaire. The online questionnaire link was distributed to all participants after they received consent to participate in this study, and the questionnaire link was closed after two weeks.

The direct medical and non-medical costs were estimated using ABC costing method. All expenses incurred for parents in managing special needs children for six months in 2019 institutional years were calculated by multiply into 2 to estimate 12 months expenses. The direct cost was estimated from service charges, food and beverages, additional costs such as parking, toll, and transportation for rehabilitation treatment of constipation. All costs incurred calculated in Ringgit Malaysia currency.

Data Analysis

This study used descriptive analysis. Mean (SD) and median (IQR) were tabulated to explain the findings. Values of $p \leq 0.05$ were considered significant. Data analysis was performed using Statistical Package Social Science (SPSS) Version 27.0 statistical software.

RESULTS

This study highlighted preliminary findings from 68 children with disabilities and their caregivers who participated in the CBR programme in 2020, met the criteria, and were recruited as a study sample. The response rate was less than 50%, this impacted of COVID-19 and Movement Control Order by Malaysia government. The findings explain the demographic characteristics of children with disabilities and their caregivers, and the direct and indirect medical and non-medical costs incurred in managing constipation.

The Sociodemographic Characteristics of Children with Disabilities

Table 2 shows the demographic data of 68 children with disabilities who participated in the CBR programme. The findings show that 43 (63.2%) participants are male, whereas 25 (36.8%) are female. The mean age of the children with disabilities in the study was 10.82 ± 3.204 , with the

highest age group being from 7 to 12 (70.6%) of the participants. For the types of disability, the disabled child with intellectual disabilities had the highest number, 20 (29.4%), while the lowest was hearing impairment, with 3 participants only

(4.4%). In addition, the severity of constipation shows that 45.59 (31 participants) complained of mild constipation, while moderate constipation and severe constipation were 33.8% and 20.6%, respectively.

Table 2: Sociodemographic of children with disabilities (N=68)

Variables		Frequency, n (%)
Gender	Male	43 (63.2)
	Female	25 (36.8)
Age	0 - 2	0
	3 - 6	4 (5.9)
	7 - 12	48 (70.6)
	13 - 18	16 (23.5)
Type of Disabilities	Hearing impairment	3 (4.4)
	Vision impairment	0
	Speech impairment	9 (13.2)
	Physical disability	16 (23.5)
	Intellectual disability	20 (29.4)
	Multiple disabilities	13 (19.2)
Duration of having constipation	Mental health conditions	7 (10.3)
	Less than six months	28 (41.2)
	6 months - 1 year	17 (25.0)
	More than one year	23 (33.8)
The severity of the constipation	Primary constipation	14 (20.58)
	Secondary constipation	54 (79.42)

The Sociodemographic Characteristics of Caregivers

Table 3 below shows data on the socio-demographics of the caregivers. Among all 68 caregivers, 42 were from the group aged 31 to 40, the highest percentage (61.8%) with a mean of 38.93 ± 6.23. Regarding educational level, most of the caregivers completed secondary school at 66.2% and tertiary educational levels at 33.8%. The study found that most caregivers were government employees, 47%, while only 20.6% were private employees. Household income from this study shows that the majority (44.1%) of the participants earned income below RM2,500, household income of RM2,501 to RM5,000 was earned by 22 participants (32.4%), RM5,001 to RM7,500 earned by 14 participants (20.6%), and 2 participants (2.9%) earned household income from RM7,501 to RM10,000. Most (80.9%) of the participants received their household income through salary, 11.8% obtained their household income from social welfare, two participants

(2.9%) from pension and 4.4% from others.

Caregivers' Costs

Table 4 tabulated the cost for caregivers in managing the constipation of their special needs children who participated in the CBR programme for the 2019 institutional year. The estimated unit costs were travelling costs to send and fetch their children to the CBR centres, attending rehabilitation at government and private hospitals, and attending alternative rehabilitation. The median cost for attending the CBR programme were of RM1,040.00 (554.84), median total costs attended public hospitals were RM 344.40 (138.72), median total costs of RM 1,255.80 (651.72) and RM 1,147.20 (701.93) for attended rehabilitation at private hospitals and alternative rehabilitation, respectively. In addition, the medial total costs for rehabilitation at private hospitals and alternative rehabilitation were among the highest costs incurred by caregivers.

Table 3: Socio-demographic of caregivers (N= 68)

Variables		Frequency, n (%)
Age	Mean ± SD	38.93 ± 6.23
	20 – 30 years	3 (4.4)
	31 – 40 years	42 (61.8)
	41 – 50 years	20 (29.4)
	51 – 60 years	3 (4.4)
District	Kuantan	39 (57.4)
	Temerloh	10 (14.6)
	Pekan	5 (7.4)
	Jerantut	4 (5.9)
	Kuala Lipis	4 (5.9)
	Raub	3 (4.4)
	Bentong	3 (4.4)
Education level	Not school	0
	Primary school	0
	Secondary school	45 (66.2)
	College/University	23 (33.8)
Occupation	Self-owned	22 (32.4)
	Government sector	32 (47.1)
	Private sector	14 (20.6)
Monthly household income, RM	Below than 2,500	30 (44.1)
	2,501 – 5,000	22 (32.4)
	5,001 – 7,500	14 (20.6)
	7,501 – 10,000	2 (2.9)
Source of income	Salary	55 (80.9)
	Social welfare	8 (11.8)
	Pension	2 (2.9)
	Others	3 (4.4)

Table 4: Caregiver costs for non-medical costs for constipation of children with disabilities (Year 2019)

Unit cost	Minimum cost (RM)	Maximum cost (RM)	Median (IQR) cost (RM)
Attending CBR Programme			
Meal fees	260.00	2,080.00	780.00 (260.00)
Additional fees	5.00	300.00	20.00 (20.00)
Transportation	43.68	982.80	436.80 (196.56)
Total Cost	43.68	2,601.52	1 040.00 (554.84)
Attending rehabilitation at a government hospital for constipation			
Food and beverages (RM)	60.00	720.00	240.00 (135.00)
Additional fees (RM)	24.00	720.00	96.00 (48.00)
Transportation (RM)	15.12	504.00	70.56 (40.32)
Total Cost	15.12	1,300.80	344.40 (138.72)
Attending rehabilitation at a private hospital for constipation			
Food and beverages (RM)	60.00	2,400.00	240.00 (240.00)
Service charge (RM)	180.00	1,200.00	600.00 (360.00)
Additional fees (RM)	36.00	1,440.00	114.00 (60.00)
Transportation (RM)	25.20	317.52	70.56 (50.40)
Total Cost	565.65	3,372.00	1, 255.80 (651.72)
Attending alternative rehabilitation for constipation			
Food and beverages (RM)	60.00	1,200.00	360.00 (165.00)
Service charge (RM)	120.00	1,800.00	600.00 (240.00)
Additional fees (RM)	36.00	1,200.00	240.00 (120.00)
Transportation (RM)	15.12	403.20	100.80 (60.48)
Total Cost	170.40	2,620.80	1,147.20 (701.93)

Medications and Supplements Costs

Other than attending rehabilitation to manage constipation problems among children with disabilities, caregivers also expense out-of-pocket costs to buy medications and supplements to reduce constipation problems. In the 2019 institutional year, caregivers spent a median of RM 890.80 (384.25) on medications and supplements per child for constipation problems.

The highest frequency of medication used to treat constipation was under the group of others, with 23 (33.8%) caregivers choosing this type of medication to treat constipation in their children with disabilities, followed by the usage of *Syrup lactulose*, with 21 (30.9%) caregivers preferring to use. Meanwhile, less than five caregivers used *Forlax*, *Sodium Valproate* and *Vitamin C* (1.5%, 1.5%, 2.9%) (Table 5).

Table 5: Caregiver costs and frequency of taking medication and supplements to treat constipation for their children with disabilities (Year 2019)

Minimum cost (RM)	Maximum cost (RM)	Median cost (IQR) (RM)
Medication And Supplements		
480.00	1,800.00	890.80 ± 384.25
Variables	Frequency (%)	
Syrup lactulose	21 (30.9)	
Syrup lactulose, Barium enema, Forlax	10 (14.7)	
Barium enema, Forlax	10 (14.7)	
Forlax	1 (1.5)	
Sodium valproate	1 (1.5)	
Vitamin C	2 (2.9)	
Others	23 (33.8)	

DISCUSSION

Children with disabilities are children who require special treatment because of developmental disorders and abnormalities experienced by children. Children with disabilities have differences that occur in several ways, such as the process of growth and development that experiences abnormalities or deviations physically, mentally, intellectually, socially and emotionally. Caregivers with children with disabilities may face more challenges in caring for their children with disabilities as compared to normal children. Government, non-government and private centres offer many rehabilitation centres in the community setting. The community-based rehabilitation (CBR) programme is one of the community programmes provided by non-government to cater to populations with many disabilities, improve their quality of life, and prevent further complications.

The average growth and development of children depends on their nutritional intake. Caregivers take care of the dietary needs of their children. It requires immense attention and additional care while looking after special needs children because they cannot express their hunger and satiety like normal children. One of the common gestational problems among special needs children is constipation (7,8). Previous

studies suggested that people with more severe intellectual disabilities, more severe physical disabilities (including dysphagia and cerebral palsy) and on multiple medications are more likely to suffer from constipation. This subset of people with intellectual disabilities needs vigilance over their bowel health (9). The current study has similar demographic data that the highest type of disabilities is among intellectual disabilities and physical disabilities as in the Table 2. Depending on the severity of the disease, children with chronic disabilities due to neurodevelopmental disorders frequently experience gastrointestinal system disorders. (10). The current study shows that children with disabilities experienced mild (45.6%) constipation. In contrast, previous studies found that the prevalence of constipation in children with CP ranges from 26% to 74% (11). These findings may be due to the types of disabilities and the number of participants in the study.

The condition of constipation substantially influences the utilisation and financial burden of healthcare services (12). Similar findings in this study showed that caregivers incurred costs for caring for their children with disabilities who experienced constipation. The highest cost was attending alternative rehabilitation for constipation treatment; caregivers spent a median of RM1,147.20 (701.93) as in the Table 4.

Constipation is a symptom of the disease. Three things that need to be considered when determining the presence of constipation are frequency, stool consistency, and physical examination results. Constipation in children aged less than or equal to four years is defined by at least one of the symptoms of defecation less than three times a week, pain during defecation, rectal impaction, and faeces in the stomach. For children over four years old, constipation is defined as a frequency of defecation less than or equal to twice a week without using laxatives, two or more episodes of soiling or encopresis in one week, or a palpable period of faeces in the abdomen or rectum during physical examination (13). The current study highlighted that the majority of the children with disabilities experienced mild constipation as in the **Table 2**; this may be influenced by their family lifestyle as the majority of the participants were from urban or suburban areas.

Constipation is mainly treated by combining treatments that are thought to be beneficial. These combinations often include changes in the individual's diet and lifestyle, including exercise for children with physical disabilities. Studies have shown that increased fibrous food and water consumption effectively treat constipation (13). A study investigating the effects of different exercises other than massage techniques in the treatment of constipation in children with Cerebral Palsy (CP) showed that there is a strong correlation between the level of spasticity and constipation in children with CP and that stretching exercises applied daily to the lower and upper extremities with five repetitions and for 30 s during six weeks for the treatment of spasticity improved the symptoms of constipation (14). The findings show that caregivers choose other medications and supplements and syrup lactulose as constipation treatments for their children with special needs as in the **Table 5**. However, the current study did not measure other combination treatments, such as abdominal massage or specific exercise, related to constipation as compared to previous mentioned study (15).

CONCLUSION AND RECOMMENDATIONS

Treating constipation in children with disabilities as soon as possible and reducing complaints are important for improving the child's quality of life and family and reducing the economic burden of complications. This study investigated the demographic and estimated the cost incurred by parents in caring for their children with disabilities who experienced constipation. In our

research, most of the children were male with intellectual disability and physical disability were among the highest group of children. A cost analysis was conducted, and the estimated cost for non-medical expenses was more than attending private rehabilitation for constipation treatment. The frequent medications taken to reduce constipation among children with disabilities in this study were others and the second most frequently taken was *Syrup Lactulose*. In conclusion, this research provides baseline data on the direct medical and non-medical costs incurred by parents in caring for children with disabilities who experience constipation. However, due to the COVID-19 pandemic and the restriction of movement, we established a preliminary study. In the future, more research should be conducted to assess comprehensive components related to constipation management for children with disabilities, including complementary treatment costs and surgery costs, and to estimate the cost-effectiveness of the constipation treatment that caregivers can choose.

LIMITATIONS

Several limitations need to be addressed in this study regarding the number of samples and study locations that should be covered for the east coast region of Peninsular to obtain robust findings. In addition, caregivers' knowledge and practices should also be assessed, and types of disabilities and their association with demographic characteristics should be employed.

ETHICAL CONSIDERATION

Ethical approval was obtained from the Kulliyyah of Nursing Postgraduate Research Committee (KNPGRC) and IREC 2020-KON2/29. The participants in this study were involved voluntarily. The study procedure was explained to the participants who had agreed to participate before they were asked to sign the consent form. They were also assured of anonymity and privacy.

Parents who agree to participate in the study must complete a consent form before answering it. The information provided by the participants will be treated as strictly confidential, and their identities will be kept anonymous.

CONFLICT OF INTEREST

The authors declare there is no conflict of interest.

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AUTHOR CONTRIBUTIONS

NNS: writing the manuscript, data collection and data analysis.

HH: involved in drafting the manuscript, data collection, support with literature content and finalizing and editing the manuscript.

SMM, HDW & EHN: review the manuscript.

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