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The Costs of Caregivers for Children with Disabilities that Participate in Centre-Based and Home-Based Community-Based Rehabilitation (CBR) Programmes in the East Coast of Malaysia

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Abstract: Rehabilitation for disabled children requires long-term programmes which are expensive to the family. This study aimed to estimate the cost incurred by caregivers' children with disabilities from Pahang, Terengganu and Kelantan participating in Community-Based Rehabilitation (CBR) (Centre-Based and Home-Based) and cost of seeking alternative rehabilitation. Cost analysis using the Activity-Based Costing (ABC) method was used to estimate twelve-months' expenditure in 2014 institutional year on 297 caregivers of children with disability, aged 0 to 18 years who attended CBR. Data were collected using a self-administered costing questionnaire and presented in median (IQR). Results showed that the median direct and indirect costs, excluding medications and alternative care were nearly four times as high in Home-Based compared to Centre-Based (RM2, 376 (11,228) vs. RM608

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(739) ($p = <0.001$). Both groups of caregivers spent a significant amount of resources on alternative rehabilitation. The high costs incurred for alternative rehabilitation is a major economic burden to the family.

Keywords: Caregiver cost, direct cost, indirect cost, community-based rehabilitation, alternative rehabilitation, disabled children.

Abstrak: Kanak-kanak kurang upaya memerlukan program pemulihan jangka panjang yang mahal buat keluarga mereka. Sewajar itu, kajian ini bertujuan untuk menganggarkan kos yang ditanggung oleh penjaga kanak-kanak kurang upaya dari Pahang, Terengganu dan Kelantan yang mengikuti program pemulihan dalam komuniti (PDK) dan kos bagi mendapatkan pemulihan alternatif. Kaedah Berasaskan Aktiviti (ABC) adalah pendekatan analisis kos yang digunakan untuk menganggarkan perbelanjaan selama dua belas bulan pada tahun penggunaan 2014 oleh 297 penjaga kepada kanak-kanak kurang upaya berumur 0 hingga 18 yang menghadiri PDK, termasuk rawatan pemulihan alternatif. Data dikumpul menggunakan soal selidik kos sendiri dan dibentangkan dalam median (IQR). Keputusan menunjukkan bahawa kos langsung dan tidak langsung median, tidak termasuk ubat-ubatan dan penjagaan alternatif hampir empat kali lebih tinggi di program yang dilakukan di rumah berbanding program yang dilakukan di pusat (RM2,376 (11,228) dan RM608 (739), $p=<0.001$). Kedua-dua kumpulan penjaga menghabiskan sejumlah besar sumber kewangan untuk pemulihan alternatif. Kos yang tinggi untuk pemulihan alternatif adalah beban ekonomi utama kepada keluarga. Oleh itu, kajian lanjut yang menilai keberkesanan kos penjagaan alternatif untuk pemulihan kanak-kanak kurang upaya adalah wajar.

Kata kunci: Kos penjaga, kos langsung, kos tidak langsung, pemulihan berasaskan komuniti, pemulihan alternatif, kanak-kanak kurang upaya

BACKGROUND

Disability has a huge meaning and impacts not only from physical, psycho-social but also pose significant economic burden to the disabled person, families, society and nations. The prevalence people with disability has increased since the last two decades from about 10% in 1970s to 15% in 2011 (World Health Organization 2014). Malaysia as a developing country is also concerned with this increasing number of disabled persons. In the year 2012, about 445,006 people with various

forms of disabilities had registered with the Department of Social Welfare Malaysia (DSWM), which this figure represented 1.5% out of 29.51 million of the country's population. The increasing number of disabled children worldwide also contributes to the statistic of persons with disability, albeit a relatively small proportion of the statistic. Malaysia also reported, that 0.1% out of 1.5% of country's population were contributed by 29,289 children (UNICEF, 2016). This proportion of the population needs long-term care that highlights an economic burden to families and nations.

The CBR programme is one of the World Health Organisation's initiatives through combined efforts of various relevant parties including people with disabilities, their families, communities, government and non-government health organizations, education, vocational and social institutions as well as other services to assist people with special needs in community settings (The United Nations Economic and Social Commission for Asia and the Pacific, 2006). Worldwide, more than 90 countries have implemented the CBR programme to cater for people with disabilities in large populations (World Health Organization, 2014) including Malaysia (Department of Social Welfare., 2012). The need for rehabilitation and the long-term process contribute to the cost of care. Although, the CBR programme has been implemented since 1970s, the cost of care for caregivers' children with disability has not been studied in detail.

Several studies have examined the cost of rehabilitation in adults, but limited data was examined in children with disabilities. The previous study highlighted that the high cost incurred from direct and indirect costs of families with disabled children to provide the best health care treatment for their disabled child (Burton & Phipps, 2009; Leonard et al. 1992; Stabile & Allin, 2012). This evidence is not surprising, because long-term rehabilitation costs associated with the disability contribute to the family's future economic performance as compared to a family with a typical child. As an example; families with a disabled child needs to buy a wheelchair that incurs additional family cost, compared to a family with typical children. This was supported by a study by Anderson et al. (2007) which found that indirect (productivity) costs lead to reduced labour force participation, leisure time and home production that contributes to economic effects of caring for children with disabilities. A study by Knapp, Romeo, & Beecham (2009) among

children with autism also highlighted the largest costs incurred from the lost productivity cost for caregivers. It is for this reason that this study focuses on caregivers' costs in caring for children with disabilities participating in the CBR programmes and alternative rehabilitation programmes.

A review of the costs incurred by caregivers of children with disabilities noted that the costs documented in the literature were varied (Stabile & Allin, 2012). Some studies only include medical cost for disabled child, but some other studies capture a broader range of costs related to the disabilities. The estimation of cost is related directly to the child's type of disability, the availability of health care services and social benefit (P. W. Newacheck, 2004). Some of studies calculated only for medical costs but, other studies capture a broader range of costs included out-of-pocket costs related to disability, and others estimate the cost of caring for children with specific diseases (Burton & Phipps, 2009; Lukemeyer et al. 2000).

To update health economic data and evaluate the current economic burden of caregivers' children with disability, we estimated the direct and indirect costs of children with disability participated in the CBR programme organised by the Department of Social Welfare Malaysia.

METHODS

This article reports on costs incurred by caregivers' children with disability for 2014 financial year. All costs involved participating in CBR programme and seeking for alternative rehabilitation treatment for both centre-based and home-based groups were calculated. The demographic characteristics of the parents, caregivers and their children with disability are also reported in this study.

Study design

This is cross-sectional study extracted from caregivers' diary for 12 months of expenditure for their children with disability. Caregivers of children with disability aged between 0 to 18 years who had registered with community-based rehabilitation programme were sampled. This is a costs analysis study conducted in selected CBR Centres from three east coast states of peninsular Malaysia that were 51, 45, and 39 CBR centres in Pahang, Terengganu, and Kelantan, respectively.

Sampling

Participants in this study were divided into two categories that are (I) disabled children and (II) caregivers. The characteristics of disabled children are any types of disability, registered with CBR programmes, holding a disability card (OKU card) and aged from 0 to 18 years were sampled. While, the characteristics for caregivers are those who have children with disabilities, who participated in the CBR programme, held the disability card (OKU card) and were aged from 0 to 18 years. The sampling method used in this study was multi-staged sampling method and universal sampling method.

Caregivers' costs

Direct and indirect costs by caregivers were estimated by using Activity-Based Costing method proposed by Drummond et al. (2005). An expenditure diary was distributed to each caregiver, and the participants were asked to estimate average expenses for all activities related to participating CBR programmes and other related rehabilitation programmes (government rehabilitation, private rehabilitation and alternative rehabilitation). Direct caregivers' costs were estimated in the study that includes money spent on 2-way transportation cost from house to CBR centre, service charges, premium group insurance (general insurance) to cover if any incident were to happen to the disabled children at the CBR centre, meal taken during trips, additional costs (toll, parking etc.), medication and supplements taken resulting from disability complications. While, indirect costs was determined from loss of productivity due to the time spent for the programme that was calculated using human capital approach. The reported salary per hour of caregivers is multiplied for 22 working days, then 8 hours to obtain the salary paid per minute. Times taken to send and fetch children to and from CBR centres and an alternative treatment centre were then calculated with salary per minute to obtain the loss of productivity cost incurred. Household income was counted according to total family income per month. Thus, caregivers who are pensioners or not employed but received monthly pension or monthly financial assistance from NGO or *Zakat* from *Zakat* Institutions (handled under Islamic State Councils), the money received was counted as household income. This assumption was an attempt to estimate monetary value to productivity

loss to the company or community as a result of participation in CBR programmes.

Data analysis

All costing data was collected for the 2014 financial year. Data were analysed using Statistical Package for Social Sciences[®] (IBM-SPSS) version 20.0. The data were analysed using *Chi-square* test and *Independent-t* test. Costs from caregivers were illustrated in median (IQR) value. The *Mann-Whitney* test was used to analyse for costing data and compare the costs between types of CBR programme: centre-based versus home-based. *P*-values less than 0.05 were considered as statistically significant.

Ethics

In terms of ethical approval, these databases were established in accordance with ethical, regulatory and legal requirements. All the ethical issues in this study were addressed. All permissions and approvals from the Ethics Committee of University Kebangsaan Malaysia (FF-2015-004) and National Medical Research Register (NMRR-15-44-24133) were obtained. This study also registered with MyResearch (JKMM 100/12/5/2: 2014/281 & JKMM 100/12/5/2/JLD 70) from the Department of Social Welfare for conducting research on their premises.

RESULTS

Among children with disabilities who participated in CBR programmes between March 2015 until April 2016, 297 met the inclusion criteria, and all caregivers agreed to participate in the present study. The calculation of sample size was based on the previous study by Khiaocharoen, et. al. (2012). The sample required were 142 per each group. Based on PS2 power and sample size programme calculation, 142 respondents were required with an additional 20% for non-response respondents (William & Walton, 2009). Thus, the estimation of sample size in this study was 342 respondents, 171 samples for centre-based care and home-based care each. Nevertheless, of these 297 participants, 160 from centre-based group and 137 from home-based group completed the study.

The socio-demographic characteristics of participants

Table 1 tabulate demographic data for 297 disabled children participated in the CBR programme. From the total participants enrolled, 160

(53.9%) participants were centre-based care and 137 participants (46.1%) were home-based care. Male participants were higher for both groups of the CBR programme, which were 101 participants (62.5%) in centre-based care and 75 participants (54.7%) in home-based care. The highest number of participants was from the age group of 0 to 12-year-old which were 131 participants (82%) and 72 participants (52.6%) for centre-based care and home-based care groups, respectively. The findings showed that there was a significant difference between the ages of the disabled children in the centre-based care and home-based care groups. This indicated that disabled children were registered with the CBR programme as early as possible to allow participation in the programme. For types of disability, the highest was shown for multiple disability for both groups of CBR of which 95 participants (59.4%) and 67 participants (48.9%) were for centre-based care and home-based care groups, respectively, demonstrating that the majority of the disabled children had a variety of disabilities that may include physical and mental disabilities.

Table 1: Demographic characteristics of disabled children

Variables	Centre-based care (N= 160)	Home-based care (N= 137)	t-test or Chi-square test	P - value
	Mean±SD or Frequency (%)	Mean±SD or Frequency (%)		
Type of CBR	160(53.9)	137(46.1)		
Gender			$\chi^2 = 1.834,$ df = 1	0.176
Female	60 (37.5)	62 (45.3)		
Male	100 (62.5)	75 (54.7)		
Age, years	8.64±3.75	11.85±4.37	$t = -6.723$	< 0.001*
0-12 years	131 (82)	72 (52.6)		
13-18 years	29 (18.2)	65 (47.4)		

Type of disability				
Hearing	1 (0.6)	1 (0.7)	$\chi^2 = 8.170,$ $df = 4$	0.086
Visual	3 (1.9)	2 (1.5)		
Physical	26 (16.3)	47 (34.3)		
Learning	35 (21.9)	20 (14.6)		
Multiple	95 (59.4)	67 (48.9)		

*significant value at $p \leq 0.05$, df = degree of freedom

The socio-demographic characteristics of caregivers were tabulated in Table 2. The results showed no significant association between the type of guidance with the different type of CBR programme ($p = 0.081$). From all of the participants enrolled: 74 were from Pahang with 51 participants (31.9%) for centre-based care and 23 participants (16.8%) for home-based care group. Terengganu recruited 50 participants (31.3%) for centre-based care and 58 participants (42.3%) for home-based care, while Kelantan had 59 participants (36.9%) for centre-based care and 56 participants (40.9%) for home-based care group. The *chi-square* test indicated there was a significant association between the states and the type of CBR programme ($p = 0.008$).

With regards to the caregivers' age, the results showed that the mean age was higher among home-based caregivers compared to centre-based group with the means 43.11 ± 9.90 and 41.08 ± 8.92 , respectively. The independent *t*-test showed that there was no significant difference between the age of caregivers and the type of CBR programme ($t = -1.86$, $p = 0.063$). The highest number of participants in an age group for centre-based care and home-based care caregivers was the age group between 41 and 50 years, with 64 participants (40.2%) and 49 participants (35.6%), respectively. The lowest number of participants in an age group for centre-based caregivers was the age group > 60 years with only one participant and for home-based care group, it was the age group between 20 and 30 years (11 participants).

The majority of caregivers were from the Malay ethnic group for both groups of participants with 156 (97.5%) participants from centre-based care and 136 (99.3%) participants from home-based care, while other ethnics, included Siamese and indigenous *Orang Asli* had four (2.5%) participants from centre-based care and one (0.7%) participant

from home-based care group. This indicated that the study participants were residing in rural areas consisting of mainly Malay villages.

In terms of educational level, this study found that the majority of the caregivers completed secondary school for educational status, which were 121 participants (75.6%) from centre-based care and 83 participants (60.6%) from home-based care group. The results showed there was a significant association between educational level and type of CBR programme with $p = 0.002$.

The highest occupation field for both groups of caregivers was housewife with 95 participants (59.4%) for centre-based care and 56 participants (40.9%) for home-based care group. The lowest occupational field was managerial with four participants (2.5%) for centre-based care and three participants (2.2%) for home-based care. There was a significant association between the occupational fields of the caregivers and the type of CBR programme at $p \leq 0.001$.

A monthly household income $< RM 5,000$ was the highest proportion for both centre-based care and home-based care groups with 152 participants (95.0%) and 131 participants (95.6%), respectively. Six participants (4.0%) from centre-based care group and five participants (3.6%) from home-based care earned a monthly household income between RM 5,001 to RM 10,000. A monthly household income $> RM 10,001$ was earned by two participants (1.2%) from the centre-based care group and only one participant (0.7%) for the home-based care group, indicating that the majority of the caregivers were with low family incomes. The category of household income was determined based on household income and basic infrastructure, which were monthly household income for the lowest group (B40), middle group (M40), and highest group (T20) (*Jabatan Perangkaan Malaysia*, 2016). These results indicated a significant association between the monthly income and the type of CBR programmes ($p = 0.001$). In terms of the source of income for caregivers, the majority received income from salary for both groups with 80% and 77.4% for centre-based care and home-based care, respectively. The lowest source of income for centre-based care caregivers was from social welfare service with two participants (1.3%), while for home-based care caregivers, three participants (2.2%) received monthly incomes from their children and Non-Government

Organisation (NGO)/religious bodies. The results showed a significant association between the source of income and type of CBR programme.

Table 2: Socio-demographic characteristics of caregivers

Variables	Centre-based care (N = 160)	Home-based care (N = 137)	t-test or Chi-square test	P- value
	Mean±SD or Frequency (%)	Mean±SD or Frequency (%)		
States			$\chi^2 = 9.542$, df = 2	0.008*
Pahang	51 (31.9)	23 (16.8)		
Terengganu	50 (31.3)	58 (42.3)		
Kelantan	59 (36.9)	56 (40.9)		
Age, years	41.08±8.91	43.11±9.89	$t = -1.864$	0.063
20 – 30 years	23 (14.4)	11 (8.1)		
31 – 40 years	50 (31.4)	48 (35.0)		
41 – 50 years	64 (40.2)	49 (35.6)		
51 – 60 years	22 (13.7)	17 (12.4)		
> 60 years	1 (0.6)	12 (8.7)		
Ethnic			Fisher's Exact test = 1.397	0.378
Malay	156 (97.5)	136 (99.3)		
Others	4 (2.5)	1 (0.7)		
Education levels			$\chi^2 = 17.775$, df = 2	0.002*
Not attend school	0	7 (5.1)		
Primary school	20 (12.5)	17 (12.4)		
Primary school	121 (75.6)	83 (60.6)		
Secondary school	19 (11.9)	30 (21.9)		
College or university				

Occupation fields			$\chi^2 = 28.471$, df = 6	< 0.001*
Professional	16 (10.0) 4 (2.5)	16 (11.7) 3 (2.2)		
Managerial	16 (10.0) 23 (14.4)	33 (24.1) 11 (8.0)		
Support	6 (3.8)	13 (9.5)		
Own business	95 (59.4)	56 (40.9)		
Unemployed	0	5 (3.6)		
Housewife				
Pension				
Monthly household income, RM			$\chi^2 = 82.04$, df = 47	0.001*
< 5,000	152 (95.0)	131 (95.5)		
5,001 – 10,000	6 (4.0)	5 (3.6)		
> 10,0001	2 (1.0)	1 (0.7)		
Source of income			$\chi^2 = 20.973$, df = 5	0.001*
Salary	128 (80.0)	106 (77.4)		
Pension	3 (1.9)	8 (5.8)		
Children	6 (3.8)	3 (2.2)		
Social welfare services	2 (1.3)	10 (7.3)		
NGO/religious bodies	0	3 (2.2)		
Others	21 (13.1)	7 (5.1)		

*Significant level at p – value < 0.05, df = degree of freedom.

Parents' and Caregivers' Costs

The distribution of the direct costs incurred by caregivers is shown in Table 3. Caregivers' costs in this study were calculated from direct and indirect costs incurred for the CBR programme and alternative rehabilitation treatments related to their children with disabilities. The results showed that the median caregivers direct and indirect costs for their child participated in the CBR programme for centre-based care

were RM 535.00 (706.00) and RM 72.73 (51.66), respectively. Direct and indirect costs for home-based care caregivers were RM 55.00 (816.00) and RM 1,927.27 (11,933.18), respectively. Total caregivers' cost for disabled children who attended centre-based care of the CBR programme was RM 607.73 (738.98), while the cost for home-based care was RM 2,375.91 (11,227.64). The cost difference was significant between centre-based care and home-based care ($p \leq 0.001$). Medication and supplement costs for centre-based care compared to home-based care was RM1,320.00 (1,978.00) and RM450.00 (877.00) respectively. The difference was not significant ($p = 0.478$). Direct cost for alternative rehabilitation for centre-based care and home-based care were RM939.18 (524.85) and RM1,826.23 (17,703.27). Indirect cost for alternative rehabilitation for centre-based care and home-based care were RM4,375.00 (7,334.00) and RM855.00 (5,851.00), respectively. Total caregivers' cost for alternative rehabilitation treatments were RM6,726.36 (7,987.00) and RM4,499.25 (25,239.00) for centre-based care and home-based care respectively. The differences between the costs were not significant ($p = 0.543$). Total caregivers' cost for the CBR programme for centre-based care was RM7,392.12 (6,848.77) and home-based care was RM8,065.53 (36,938.78). The differences of the costs were significant with p -value < 0.001 (Table 3).

Table 3: Direct and indirect costs of caregivers per year

Type of Cost	CBR Programme		Mann Whitney test, Z	P-value
	Centre-based care	Home-based care		
	Median (IQR)			
Direct cost (RM)	535.00 (706.00)	55.00(816.00)	-10.578	< 0.001*
Indirect cost (RM)	72.73(51.66)	1,927.27 (11,933.18)	-10.346	< 0.001*
Total CBR cost per year (RM)	607.73 (738.98)	2,375.91 (11,227.64)	-8.830	< 0.001*
	<u>Medications and supplements</u> Median (IQR)			
	1,320.00 (1,978.00)	450.00 (877.00)	-0.709	0.478

	<u>Alternative Rehabilitation</u>			
	Median (IQR)			
Direct cost (RM)	939.18 (524.85)	1,826.23 (17,703.27)	-3.926	< 0.001*
Indirect cost (RM)	4,375.00 (7,334.00)	855.00 (5,851.00)	-0.494	0.621
Total Alternative cost per year (RM)	6,726.36 (7,987.00)	4,499.25 (25,239.00)	-0.608	0.543
Total caregivers' cost per year (RM)	7,392.12 (6,848.77)	8,065.53 (36,938.78)	-5.504	< 0.001*

Table 4 tabulated the cost components incurred by caregivers for each CBR programme. The highest mean direct cost incurred by centre-based caregivers was contributed by additional cost derived from alternative rehabilitation treatment with mean values of RM2,981.60 (RM4.00 – RM14,400.00) and for home-based caregivers was contributed from food costs derived from private rehabilitation treatment with mean values RM2,430.00 (RM 60.00 – RM4,800.00). The lowest mean direct cost incurred by centre-based care caregivers was on additional costs for CBR programme at RM72.17 (RM 60.00 – RM 100.00), while for home-based care was on insurance costs with the mean of RM54.48 (RM 50.00 – RM 55.00). However, no additional costs and transportation costs were incurred for home-based care caregivers as the CBR workers will conduct home visits. This finding reported that a high cost was incurred by centre-based care caregivers compared to home-based care. Refer to table 4 for details of costs.

Table 4: Comparison of unit cost for caregivers' mean cost by components (2014)

Unit cost	Centre-based			Home-based		
	Mean cost (RM)	Minimum cost (RM)	Maximum cost (RM)	Mean cost (RM)	Minimum cost (RM)	Maximum cost (RM)
CBR Programme						
Insurance	54.28	50.00	55.00	54.48	50.00	55.00

Additional	72.17	60.00	100.00	-	-	-
Transportation	568.63	24.00	3,840.00	-	-	-
Government rehabilitation						
Additional	102.80	2.00	818.00	126.66	20.00	480.00
Transportation	200.36	6.00	1,280	1,080.14	20.00	9,600.00
Food	172.90	20.00	1,080.00	672.81	20.00	2,400.00
Private rehabilitation						
Treatment	452.72	60.00	1,440.00	404.00	40.00	1,400.00
Additional	67.60	4.00	200.00	500.00	500.00	500.00
Transportation	166.31	20.00	400.00	490.00	20.00	2,400.00
Food	130.00	20.00	360.00	2,430.00	60.00	4,800.00
Alternative rehabilitation						
Treatment	354.78	40.00	2,400.00	441.25	40.00	2,400.00
Additional	2,981.60	4.00	14,400.00	1502.00	4.00	3,000.00
Transportation	565.47	10.00	7,200.00	1,039.64	10.00	7,200.00
Food	559.50	10.00	2,400.00	650.00	10.00	2,400.00

DISCUSSION

This study evaluated costs from caregivers for their children with disability that participated in CBR programmes (centre-based care and home-based care), government rehabilitation facilities, private rehabilitation and alternative rehabilitation programmes. All expenses were calculated based on the 2014 financial year.

The caregivers' costs incurred from direct and indirect costs spent for participation in the CBR programme and other alternative rehabilitation treatments were calculated. In this study, the median total caregivers' cost for CBR programme was higher among home-based care compared to centre-based care, RM2,375.91 (11,227.64) vs. (RM607.73 (738.98), respectively (p value < 0.001). The median direct and indirect costs,

excluding medications and alternative care was nearly four times as high in home-based group compared to centre-based group RM 2,376 (11,228) vs. RM 608 (739) ($p \leq 0.001$). Caregivers in the centre-based group spent RM1,320 (1,978) on medication and supplements compared to only RM450 (877) for those in home-based group. Both groups of caregivers spent significant amount of resources on alternative care. Although the cost of alternative rehabilitation treatment is 90.9% of the total cost for centre-based care group compared to 55.8% in the home-based care group, the difference was not significant (p -value = 0.543). The findings were contrary to a study by Sharif Azar et al. (2015) that reported the average cost of caring for cerebral palsy children in the home-based care centre was lower than centre-based (US\$ 660.3 vs. US\$933.8, $p = 0.001$). However, the previous study does not include the indirect costs that may have contributed to the cost of the programme.

Previous studies highlighted that high costs incurred from direct and indirect costs of families with disabled children to provide the best healthcare treatment for their child (Burton & Phipps, 2009; Leonard et al. 1992; Stabile & Allin, 2012). This evidence is not surprising, because long-term rehabilitation costs associated with children with disabilities contribute to the family's future economic performance as compared to families with typical children. As an example; a family with a disabled child needs to buy wheelchair that incurs additional family expense, compared to a family with typical children. This was supported by Anderson et al. (2007) who found that indirect (productivity) costs lead to reduced labour force participation, leisure time and home production that contribute to the economic effects of caring for children with disabilities.

A review from the literature documented the costs incurred by caregivers' children with disability varies. Some studies only include medical costs for disabled children, but other studies captured a broader range of costs related to disabilities. The estimation of cost is related directly with the child's type of disability, the availability of health care services and social benefits. Some of studies calculated only for medical costs but, other studies capture a broader range of costs included out-of-pocket costs related to disabilities, and others estimate the cost of caring for children with specific diseases (Burton & Phipps, 2009; Lukemeyer et al. 2000). In addition, many other costs related to disability studies have

been performed in several western countries only (Weiss & Sullivan, 1998), this make comparisons difficult for the Malaysian setting.

The components costs used varies based on the studies and populations investigated, this makes comparisons in different studies difficult (Newacheck et al. 2004). Although the costs were different in components for calculation purposes but the broader range was notable. A comprehensive literature study identified, although the estimates vary from one family to another, the evidence points to the high costs spent for families with children with disability that is significant particularly on out-of-pocket expenditures included medications, supplements (Stabile & Allin 2012) and other alternative rehabilitation treatments.

The findings show higher expenditure by caregivers who go for alternative rehabilitation for their disabled children. The increasing out-of-pocket cost may have contributed to the economic burden of the families seeking for Complementary Alternative Medicine (CAM) associated with psycho-socioeconomic factors. This finding is similar with the current study that examines the majority of participants staying in villages or sub-urban areas, whose psycho-socioeconomic may influence their practice in daily life. A study on CAM used among selected rural communities in Malaysia found that the use of CAM was significantly higher in Malays, unemployed occupants with household incomes less than MYR2,500 per month (Ganasegeran et al. 2014). Comparable trends in the current study were found with the higher direct cost expenses for alternative rehabilitation treatment among those in the home-based group, where the majority of the caregivers have a single source of income as most of the mothers of the home-based care were housewives. A study by Ching et al. (2013) particularly in primary -care settings. This study seeks to understand the prevalence, types, expenditures, attitudes, beliefs, and perceptions of CAM use among patients with DM visiting outpatient primary care clinics.

METHODS: This is a descriptive, cross-sectional study of 240 diabetic patients. CAM is defined as a group of diverse medical and healthcare systems, practices, and products that are not generally considered part of conventional Western medicine. Data analysis was done using SPSS v. 19 and multiple logistic regressions were used to identify predictors of CAM use.

RESULTS: The prevalence of CAM use was 62.5 percent. Female were 1.8 times more likely than male in using CAM. Malays (75% found that the usage of CAM was higher among females

than males. This is parallel to the current study that mothers were a major role player in taking care of their disabled children. This situation may influence decision making for seeking alternative rehabilitation treatments for their children.

Conclusion

This is the first study, which assessed the caregivers' costs for children with disabilities who participated in CBR programmes and sought alternative rehabilitation treatments. Although this programme was implemented in over 90 countries throughout the world to address the needs of people with disabilities and communities, there was scarce data on the country's implementation and burden of care. The results indicated that costs incurred for CAM was high. Besides, the majority of CAM are mostly unproven in terms of evidence, and not sanctioned therapies by Ministry of Health. The results estimated the average proportion of their monthly income spent on CAM contributing to the magnitude of the economic burden of the family. The financial burden of the family, as tabulated in the findings, is an issue which health care providers and policymakers need to address to make CBR programmes more effective. This study suggests for the improvement of care services and increased awareness among caregivers to be more discerning in spending their money to choose CAM. Thus, it is critical for policy-makers and researchers to explore caregivers of children with disabilities, awareness on the usage of CAM which would benefit in reducing the financial burden of the family.

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Authors' contributions

HH contributed to the whole of the study by guidance from AMN and SMA. SMA and AMN reviewed and approved the final version of the manuscript.

Competing interest

The authors declare that they have no competing interests.

References

- Anderson, D., Dumont, S., Jacobs, P., & Azzaria, L. (2007). The personal costs of caring for a child with a disability: A review of the literature. *Public Health Reports*. <https://doi.org/10.1177/003335490712200102>
- Burton, P., & Phipps, S. (2009). Economic costs of caring for children with disabilities in Canada. *Canadian Public Policy*, 35(3), 269–290. <https://doi.org/10.3138/cpp.35.3.269>
- Ching, S. M., Zakaria, Z. A., Paimin, F., & Jalalian, M. (2013). Complementary alternative medicine use among patients with type 2 diabetes mellitus in the primary care setting: A cross-sectional study in Malaysia. *BMC Complementary and Alternative Medicine*, 13. <https://doi.org/10.1186/1472-6882-13-148>
- Department of Social Welfare. (2012). Program Pemulihan Dalam Komuniti. Retrieved January 20, 2014, from http://www.jkm.gov.my/content.php?pagename=program_pemulihan_dalam_komuniti_pdk&lang=bn
- Ganasegeran, K., Rajendran, A. K., & Al-Dubai, S. A. R. (2014). Psychosocioeconomic factors affecting complementary and alternative medicine use among selected rural communities in Malaysia: A cross-sectional study. *PLoS ONE*, 9(11). <https://doi.org/10.1371/journal.pone.0112124>
- Jabatan Perangkaan Malaysia. (2016, October 9). Laporan Penyiasatan Pendapatan Isi Rumah Dan Kemudahan Asas 2016. *Sumber Statistik Rasmi Malaysia*, pp. 11–97. Retrieved from http://www.statistics.gov.my/portal/index.php?option=com_content&view=article&id=1640&Itemid=111&lang=bn
- Khiaocharoen, O., Pannarunothai, S., Riewpaiboon, W., Ingsrisawang, L., & Teerawattananon, Y. (2012). Economic Evaluation of Rehabilitation Services for Inpatients with Stroke in Thailand: A Prospective Cohort Study. *Value in Health Regional Issues*, 1(1), 29–35. <https://doi.org/10.1016/j.vhri.2012.03.021>
- Knapp, M., Romeo, R., & Beecham, J. (2009). Economic cost of autism in the UK, 13(December 2015), 317–336. <https://doi.org/10.1177/1362361309104246>
- Leonard, B., Brust, J. D., & Sapienza, J. J. (1992). Financial and time costs to parents of severely disabled children. *Public Health Reports (Washington, D.C. : 1974)*, 107(3), 302–312.
- Lukemeyer, A., Meyers, M. K., & Smeeding, T. (2000). Expensive children in poor families: Out-of-pocket expenditures for the care of disabled and chronically ill children in welfare families. *Journal of Marriage and Family*. <https://doi.org/10.1111/j.1741-3737.2000.00399.x>

- Newacheck, P. W., Inkelas, M., & Kim, S. E. (2004). Health Services Use and Health Care Expenditures for Children With Disabilities. *Pediatrics*, *114*(1), 79–85. <https://doi.org/10.1542/peds.114.1.79>
- Sharif Azar E, Ravanbakhsh M, Torabipour A, Amiri E, H. M. (2015). Home-based versus center-based care in children with cerebral palsy : a cost-effectiveness analysis, *8*(4), 245–251.
- Stabile, M., & Allin, S. (2012). The economic costs of childhood disability. *The Future of Children*, *22*(1), 65–96. <https://doi.org/10.1353/foc.2012.0008>
- The United Nations Economic and Social Commission for Asia and the Pacific. (2006). Disability. Retrieved July 11, 2014, from <http://www.unescap.org/esid/psis/disability>.
- UNICEF. (2016). *Inspirasi. United Nations Children's Fund*. Malaysia.
- Weiss, K. B., & Sullivan, S. D. (1998). The health economics of asthma and rhinitis . I . Assessing the economic impact, 3–8. <https://doi.org/10.1067/mai.2001.112262>
- William, D. Dopont and Walton, D. plummer. (2009). PS Power and Sample Size Calculation.
- World Health Organization. (2014). Disability and Health. Retrieved February 4, 2014, from <http://www.who.int/mediacentre/factsheets/fs352/en/>

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