

ORIGINAL ARTICLE

THE ECONOMIC BURDEN OF FAMILIES OF CHILDREN WITH CEREBRAL PALSY IN MALAYSIA

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ABSTRACT

The economic burden of children with cerebral palsy exceeds far beyond the needs of typical children leading to physical and mental stress to their parents. The study aims to examine the economic burden of parents of children with cerebral palsy in Malaysia. Calculation is made using a cost of illness approach due to cerebral palsy disorders that includes direct healthcare costs, direct non-healthcare costs, developmental costs and indirect costs. Using convenient sampling method, a total of 74 parents completed questionnaires through online or hard copies. Direct healthcare costs represent the highest cost of RM14, 715.49, followed by the developmental costs of RM10, 146.07, RM2, 674.00 for direct non-healthcare costs and RM2, 175.20 for indirect costs. So the total cost of financing for the needs of a child with cerebral palsy is RM29, 710.76 per year. This is a huge and burdensome amount for their parents. The findings of this study may assist policy makers in their planning of effective service provision to suit the needs of parents of children with cerebral palsy in Malaysia.

Keywords: economic burden, cerebral palsy, parents, children with cerebral palsy

INTRODUCTION

Cerebral Palsy (CP) is a permanent disorder that causes the movement and posture of an individual's body to be limited^{1,2}. In addition, individuals with CP also suffer from other health problems commonly known as comorbid that affect the quality of the individual's life³. Limited movements and comorbid issues require individuals with CP to undergo rehabilitation and treatment services for long period of time^{2,4}.

According to research, children who experience limitations in daily activities require two to three times higher medical services than typical children^{5,6}. A child with CP incurs a mean total average lifetime healthcare costs of US\$22,143.00, whereas a child without any lifetime healthcare needs only incurs costs of US\$1,729.00, approximately 13 times lower⁴. Meanwhile, lifetime healthcare cost of a child with CP in South Korea was calculated to be US\$26,383.00, which is 1.8 times the basic lifetime healthcare cost of the general population, US\$14, 579.00².

These healthcare needs lead to a higher cost of caring for children with CP as compared to children who are typically developing^{7,8,9} and the total cost often exceeds family's expectation. Due to the complex care that a child with CP needs, there have

been numerous studies undertaken to identify the expenses that the family of children with CP needs to bear^{10,11}. Previous studies have found that children with CP often suffer from fall injury. Therefore, parents opted to pay for higher and better caregiving services to avoid unwanted injuries¹². Cost of illness approach is a commonly used approach in calculating economic burden^{7,13,14}. According to this approach, the economic burden of an illness refers to all expenditure estimated to be avoided if one illness is prevented¹⁵.

A study carried out in China in 2003 reported that the average of lifetime economic burden for a CP case was US\$67,044⁷. Meanwhile, a study of economic burden in Denmark and United State indicated that every CP case in the country requires an average lifetime expenditure of US\$1,186,107.11 and US\$912,000.00^{11,16}. Comparison in previous studies found that average lifetime cost for direct healthcare costs carried by a family of a child with CP in the United States was US\$92,000.00, Denmark US\$74,000.00, South Korea US\$26,383.00 and China US\$2,011.00². The attributable lifetime cost was calculated until the age of 70¹¹.

METHODOLOGY

This study is a cross-sectional quantitative study where convenient sampling techniques were used in

respondent selection based on several inclusive and exclusive criteria. The inclusive criteria are i) having a child diagnosed with CP; ii) families originating or residing in Malaysia; iii) able to speak and write in Malay; and iv) able to use internet or postal service. Whereas the exclusive criteria are i) family with more than one child of CP or family member with disability; and ii) families with more than one child or family members suffering from chronic illness and requiring long-term care. However, these criteria are excluded as it will make the amount of expenditure larger, while the purpose of the study is to calculate the economic burden incurred by each family to raise a child who only has CP.

Information regarding family expenditure is collected using Parents' Financial Statements Form that had been adapted from the Out-of-pocket Expenses survey¹⁷. This form is divided into 5 parts which are; Part I Parents' Demographic Information; Part II Children with CP Demographic Information; Part III and IV Expenditure List; and Part V Parents and Child with CP Productivity Loss.

Items in Part III and IV consist of expenditure list for direct cost and developmental cost. Direct cost consists of all expenditure related to medical treatment of illness¹⁸. There are two categories of direct costs which are direct healthcare costs and direct non-healthcare costs. Direct healthcare costs are expenditures for medical treatment sources that used to treat or overcome condition complication of an individual such as outpatient services, warded fees, diagnoses, medical treatment, surgery, medication and rehabilitation services. Meanwhile, direct non-healthcare costs include transportation and accommodation cost related to the usage of medical services facilities¹⁴.

Developmental costs refer to expenditure for special needs education, special diet, supplementary diet and CP child care services⁷. Meanwhile, item in Part IV is about indirect cost consisting of parents' productivity loss and children with CP productivity loss^{10,19,20,21}. A pilot survey has been carried out to identify the compatibility of Parents Financial Statement Form and improvements have been done based on the pilot survey. Next, the form was distributed online through email and private message and social media such as Facebook. Data obtained is analysed using average comparison and non-parametric Kruskal-Wallis and Mann Whitney U test.

FINDINGS AND DISCUSSION

A total of 74 parents who are members of the Malaysian Advocates for Cerebral Palsy (MyCP)

association completed the Parent Financial Statement Form online. Based on the analysis carried out, the mean of children with CP age in this study is 5.75 years old. For gender factor, 52.7% of research subjects are male. Descriptive statistical analysis for racial factor, shows that Malay is the majority with 87.9%, followed by Chinese 6.8% and other race 5.4%. Apart from that, 63.5% of CP child with comorbid illness and 36.5% are without comorbid illness.

The average family household income of families of children with CP is RM3,374.29/month for year 2013. Comparison their household income with average Malaysian household income²² shows that 14.9% of families of children with CP have household income exceeding average of state household income. Around 35.1% children with CP in this study received free treatment from government health clinics and hospitals. 48.6% of the research participants were receiving monetary assistance from Social Welfare Department (JKM) through Financial Assistance for Carers of Bed-Ridden Disabled (OKU) and Chronically Ill (BPT) or from the Ministry of Education Malaysia (KPM) for children with disability studying in school. A previous study showed that there was no relationship between household income and quality of life among teenagers with disabilities²³.

Average Family Economic Burden Category Cost

Based on Table 1, average cost incurred by families of children with CP in 2013 was RM29,710.76. Overall, direct healthcare costs is the highest burden even though Malaysians receive medical services at government hospitals and health clinics. On average, families of children with CP spend RM14,715.49 for direct healthcare costs, RM10,146.07 for developmental costs, RM2,674.00 for direct non-healthcare costs and RM2,175.20 for indirect costs.

Comparison of components in the medical direct cost category showed that the average cost of rehabilitation services was the highest despite the government providing this service for free. The analysis found that two-thirds of children with CP received rehabilitation services at private institutions due to parents' work commitments, more frequent appointments and long waiting lists at government hospitals. While another 1/3 relied fully on rehabilitation services at government hospitals.

The alternative treatment component is the second highest in the medical direct cost category of RM2,836.22. This showed that there is a high interest among parents to explore new treatment

modalities for CP disorders²⁴. About two-third chose alternative treatments such as acupuncture, traditional massaging, cupping treatment, stimulotherapy, aqua therapy, homeopathy and others for their child. Parents believed that alternative treatment able to improve the quality of their child's life, improving effectiveness of CP treatment and reducing the symptoms of CP²⁵.

Purchase of assistive device is among the top three in the category of direct medical costs. In Malaysia, children with CP who are registered with the Malaysian Welfare Department (JKM) as a person with disabilities, are eligible to receive financial assistance to buy walking aids or other assistive devices. The financial assistance is under a Procurement of Artificial Limbs and Orthopaedic schemes (BAT/AS). However, this scheme has limitations as it does not cover purchases of spare parts or maintenance services. In addition, purchase of assistive device through this scheme takes longer than the immediate purchase.

The second highest average cost is the cost of development. Under the development component cost, the cost to buy dietary supplement is the highest at RM3,837.10. Parents spent the most expenditure in purchasing special formula milk, supplementary diet, nasogastric tube, milk pump and others. Daily essentials cost burden is the second highest totalling RM2,235.95, consisting of the cost for purchasing special shampoo, lotion and body wash for sensitive skin, special toothpaste, wet tissue as well as diapers. Home helpers component is the third highest at RM1871.35.

Third highest average cost is direct non-healthcare costs with the value of RM2,674.00. For indirect cost, it is only for a child with CP who has reached the age to work which is 16 years old according to Children and Young Persons (Employment) Act 1966. However, all the children involved in this study were still in school. Hence, individual productivity loss cost only accounted for the days of year-end holidays. For parents' productivity loss cost, around 62.2% of participating parents had taken unpaid leave to take care of their CP child. Not only that, about 20.3% of study participants or their spouse had to resign from their job to take care of their

child with CP. Average of parents' productivity lost in this research is about RM2,175.20.

Comparison of Economic Burden According to Age Group

Based on Table 2, the economic burden of children with CP in the age group 7-12 years was highest at RM45,884.23, followed by age group 13-18 years old at RM31,969.04, then age group 4-6 years old at RM25,589.99 and age group 0- 3 years at RM19,976.11. Kruskal-Wallis test carried out found that there are no significant differences in terms of economic burden of children with CP between age groups.

Average comparisons based on the economic burden category found significant differences between the cost of development and the age group of children ($p = 0.002$). The Mann-Whitney U test showed that the difference was significant between the age group 0-3 years and the age group 4-6 years ($p = 0.0005$) and between the 4-6 year age group and the age group 7-12 years ($p = 0.046$). The analysis carried out on the cost component of the development shows that there is a significant difference between special education and special diet among the children with CP age group, $p = 0.019$ and $p = 0.021$.

Special education costs are highest for age group 13-18 years, followed by age group 7-12 years (1.54 times) and age group 4-6 years (1.85 times). This study have found that there is no special educational expenses for the age group 0-3 years. This indicates that early intervention services are rarely accessed by parents in Malaysia. Children with CP who do not receive special early intervention services, will incur higher treatment costs as their age increase. Most parents only bring their child for check-up when the child shows a significant CP symptom. Early intervention services are important to ensure that the movement of the functional motor of the CP children develops and consequently does not affect the prognosis of their motor system when grown up²⁶. Access to early intervention services can reduce future educational expenses.

Table 1 : Parents' economic burden

	Minimum	Maximum	Min	Standard Deviation
Direct Healthcare Cost (RM)				
Rehabilitation Services	0.00*	564,000.00	10,080.00	65,446.64
Alternative Treatment	0.00*	24,000.00	2,836.22	5,049.68
Medicine Cost	0.00*	400.00	40.00	84.08
Purchase of Medical Aid	0.00*	8,150.00	1,453.85	1,815.88
Diagnostic Test	0.00*	1,500.00	107.26	309.77
Ward Entrance Fee Surgery	0.00*	6,000.00	104.33	705.44
Consultation Fee	0.00*	6,005.00	100.77	713.06
Total	0.00*	573,990.00	14,715.49	66,568.08
Direct Non-Healthcare Cost (RM)				
Transportation Cost	-	14,400.00	2,674.00	3,145.01
Accommodation Cost	-	-	-	-
Total	-	14,400.00	2,674.00	3,145.01
Developmental Cost (RM)				
Domestic Helper	-	10,800.00	1,871.35	2,763.39
Nursery	-	10,200.00	608.11	1,746.47
Special Education	-	5,400.00	483.24	1,179.44
Dietary Supplement	-	18,840.00	3,837.10	3,136.17
Daily Necessities	-	6,000.00	2,235.99	1,544.25
Insurance	-	24,000.00	1,083.78	3,776.48
Others	27.00	1,500.00	245.13	508.63
Total	1,200.00	31,200.00	10,146.07	7,054.85
Indirectly Cost (RM)				
Parents and Child	-	48,153.85	2,175.20	7,390.69
Productivity Loss	-	-	-	-
Total	-	48,153.85	2,175.20	7,390.69
OVERALL TOTAL			29,710.76	

The difference in dietary supplement burden according to age group is also significant ($p = 0.021$). This expenditure is the highest for child with CP in age group of 13- 18 years old, followed by 4-6 years old age group (1.59 times), age group of 0 - 3 years old (2.11 times) and 7-12 years old age group (3.20 times). Children with CP are at higher risk to suffer eating problems such as difficulties to chew, vomits, recurring lung infection and gastroesophageal reflux illness²⁷. About two-third of CP child in this study requires special formula milk and supplementary diet due to digestive problems. There was a small number of respondents who only ate porridge and/or soft texture cereal due to motor problem at the muscles that functioning to chew and swallow. Whilst, a smaller group of these children depend on nasogastric tube for daily nutrient intakes.

The comparison of direct healthcare cost according to economic burden category showed the highest in age group 7 - 12 years old, followed by age group of

13 - 18 years old (2.56 times), age group of 4 - 6 years old (4.35 times) and age group of 0 - 3 years old (4.88 times). These findings vary if compared with the finding of a study carried out in United States of America⁴, Denmark¹¹, South Korea² and China⁷ that found child at 0-6 years old age group bears the highest direct medical cost compares to other groups.

Analysis for direct healthcare cost found that there is a significant difference among consultation fees and child age group ($p = 0.032$). Age group of 7-12 years old carried the highest expenditure for consultation fees followed by age group of 13 - 18 years old (2.08 times), age group of 0 - 3 years old (25.13 times) and age group of 4 - 6 years old did not carry the consultation fees cost. Based on Mann-Whitney test, the differences are significant between age group of 0 - 3 years old with age group of 4 - 6 years old ($p = 0.0005$).

Economic burden comparison for direct non-medical cost found out that age group of 4 - 6 years old record the highest amount, followed by age group 13 -18 years old (1.29 times), and followed by age group of 2 - 12 years (1.42 times) as well as age group of 0 - 3 years old (1.69 times). Indirect cost is the highest for age group 0 - 3 years old which is 1.94 times of cost bear by age group of 13 - 18 years old, 9.60 times of cost bear by age group of 7 - 12 years old.

Economic Comparison According to Household Income Group

Based on Table 3, it was found that below average household income bear higher expenditure compared to above average household income which is RM30,378.09. However, the analysis done found that there were no significant differences between these household income group ($p = 0.317$). Below average household income group recorded the highest total average cost for direct medical cost and indirect medical cost category.

Below average household income group bears direct medical cost 1.55 times more than above average household income group. Analysis carried out on direct medical cost components showed, below average household income group allocated more expenditure for rehabilitation and medication which is 4.19 times and 1.33 times. Whilst, above average household income, allocated more expenditure on alternative treatment (1.28 times), ward entrance fee and/or surgery (20.93 times) and purchasing of medical aid (2.72 times).

Analysis carried out found that there is significant difference between household income groups with purchasing of medical aid ($p = 0.011$). Above average household income group bears higher purchasing of medical aid cost compared to lower

household income group because they can afford medical aid. Despite having duty import exemption benefits for replacement aid and artificial/support aid given to OKU card holder, but families of children with CP still have to bear the cost of replacement aids and delivery cost of replacement aid from overseas²⁸.

For developmental cost, the above average household income group spent 1.26 times more than below average household income. Above average household income allocated more expenditure for special diet (1.60 times), maids (2.36 times), daily necessities (1.14 times) and special education (1.30 times). Results of the analysis found out that there is significant between household income group with maid component ($p = 0.028$) and special diet ($p = 0.023$).

This finding showed that, the above average household income group chose to hire home helpers to take care of their child with CP while they work. This explanation is strengthened when it was found that no family of above average household income group had daily nursery expenses. Apart from that, family from above average household income were also able financially to pay for a home helper; which is two to three times more than a daily nursery fees. Majority of the children with CP from the above average household income suffers comorbid illness and aged around 4-6 years old or 13-18 years old which is the age group that bear higher special diet cost. On contrary, only a quarter of them aged around 4-6 years old or 13-18 years old.

For direct non-healthcare cost, both groups spent almost the same total amount, RM2,683.64 for above average household income group and RM2672.32 for below average household income

group. For indirect cost, below average household income spent 1.22 times more than above average household income.

Table 2: Comparison of CP economic burden according to age group

Economic Burden Categories/ Age	0-3 years old	4-6 years old	7-12 years old	13-18 years old	Kruskal-Wallis (p) Test ⁹
Direct Healthcare Cost(RM)					
Rehabilitation Services	2,073.60	2,347.20	28,227.27	7,200.00	0.165
Alternative Treatment	3,216.00	3,072.00	2,116.36	3,060.00	0.361
Medicine Cost	41.88	42.16	39.05	0*	0.710
Purchase of Medical Aid	1,114.20	1,358.80	1,868.64	2,325.00	0.341
Diagnostic Test	188.00	104.17	28.64	0*	0.743
Ward Entrance Fee Surgery	25.64	289.58	0*	0*	0.285
Consultation Fee	12.50	0*	312.14	150.00	0.032*
Total	6,672.82	7,213.91	32,592.10	12,735.00	0.425
Direct Non-Healthcare Cost (RM)					
Transportation Cost	2,055.36	3,474.56	2,464.91	2,700.00	0.658
Accommodation Cost	-	-	-	-	-
Total	2,055.36	3,474.56	2,464.91	2,700.00	0.658
Developmental Cost (RM)					
Domestic Helper	1,056.00	2,697.60	1,854.55	1,920.00	0.065
Nursery	134.40	888.00	883.64	0	0.101
Special Education	0.00	648.00	780.00	1,200.00	0.019*
Dietary Supplement	3,693.79	4,896.00	2,436.38	7,800.00	0.021*
Daily Necessities	1,988.93	2,363.04	2,139.27	4,800.00	0.208
Insurance	343.00	1,307.80	1,769.55	0	0.333
Others	73.33	57.00	542.33	0	0.755
Total	7,289.45	12,857.44	10,405.72	15,720.00	0.002*
Indirect Cost (RM)					
Parents and Child Productivity Loss	3,958.48	2,044.08	421.50	814.04	0.794
Total	3,958.48	2,044.08	421.50	814.04	0.794
OVERALL TOTAL	19,976.11	25,589.99	45,884.23	31,969.04	0.392

* Survey participants received free medical services from Malaysia’s hospital or health clinic or does not have the needs to receive certain medical services.

Economic Burden Comparison Between Comorbid Group

Based on Table 4, group with comorbid illnesses bear total expenditure of RM31,805.24, whereby the amount is higher compared to group with no comorbid illnesses. Comparison between economic burden categories found that, group with no comorbid illness bear higher expenditure for direct non-healthcare cost (1.32 times), developmental cost (1.11 times) and indirect cost (2.99 times) compared to group with comorbid illnesses. However, for direct healthcare cost, group with comorbid illnesses bear higher cost compared to group without comorbid illnesses which is 2.17 times more. Findings of this study is similar with the findings of previous study⁴. The study reported that

a family of a child with CP with comorbid illnesses have to bear direct medical cost amounting to US\$43,338.00/year, compared to a child with CP without comorbid illnesses, US\$16,721.00/year.

Comparison between comorbid groups for direct healthcare cost found group with comorbid illnesses allocated higher expenditure for rehabilitation service (4.15 times), purchasing medical aid (1.63 times) and diagnostic test cost (1.73 times). Meanwhile, group without comorbid illnesses allocated higher expenditure for alternative treatment (1.40 times), medicine (1.17 times), ward entrance fee and/or surgery (6.33 times) and consultation fees (17.80 times).

Table 3: Comparison CP economic burden according to household income group

Economic Burden Category / Household Income	Above Average	Below Average	Mann-Whitney U (p) Test
Direct Medical Cost (RM)			
Rehabilitation Services	2,710.91	11,366.67	0.967
Alternative Treatment	3,480.00	2,723.81	0.698
Medicine Cost	31.27	41.53	0.749
Purchase of Medical Aid	3,146.82	1,158.25	0.011*
Diagnostic Test	109.10	106.94	0.699
Ward Entrance Fee Surgery	545.45	26.06	0.976
Consultation Fee	0	117.30	0.263
Total	10,023.55	15,540.56	0.384
Direct Non-Healthcare Cost (RM)			
Transportation Cost	2,683.64	2,672.32	0.062
Accommodation Cost	-	-	-
Total	2,683.64	2,672.32	0.062
Developmental Cost (RM)			
Domestic Helper	3,676.36	1,556.19	0.028*
Nursery	0	714.29	0.101
Special Education	600.00	462.86	0.957
Dietary Supplementary	5,517.82	3,453.64	0.023*
Daily Necessities	2,505.82	2,188.88	0.933
Insurance	0	1,273.02	0.074
Others	0	280.14	0.124
Total	12,300.00	9,929.02	0.406
Indirect Cost (RM)			
Parents and Child Productivity Loss	1,825.91	2,236.19	0.831
Total	1,825.91	2,236.19	0.831
OVERALL TOTAL (RM)	26,833.10	30,378.09	0.317

Based on the study, a child with CP with comorbid illnesses required higher medical aid expenditure compared to a child with CP without comorbid illness²⁷. This is because children with CP have different medical aid needs according to their level of development and impairments. Purchasing and changing medical aid are essential to maintain a child with CP’s health and level of independent for daily activities²⁹. A lack of local medical aid and experienced technician in handling medical aid should be taken into consideration by the government to reduce the burden faced by families of children with CP.

For developmental cost, it is found that the group of families with comorbid illness allocated higher expenditure for only dietary supplement component about 1.34 times higher than group without comorbid illnesses. Whilst, group without comorbid illnesses allocated higher expenditure for home helpers (1.24 times), daily nursery fees (5.76 times), special education cost (1.03 times),

insurance (1.67 times) and ‘others’ cost (8.98 times). Analysis carried out there is a significant difference between comorbid groups with daily nursery component ($p = 0.024$). This is because majority of parents from group with comorbid illnesses chose to resign and take care of their child with CP on their own.

Overall, the group without comorbid illnesses incurred higher expenditure cost compared to those with comorbid illnesses. This situation occurs as many parents of the group with comorbid illnesses choose to resign, have a lower average household income and receive financial aid from the government. Due to issue of forced resignation, most parents suggested, that they should be given the opportunity to work from home or given more flexible working hours. This suggestion that the decision to resign to care for the child at home could reduce the cost of a particular cost but the household income would suffer. Economic burden not only cause a financial strain to the family but

also give negative impact to the Quality of Life (QOL) of family. The study shows the QOL of

mothers of children with CP is significantly lower than in mothers of typically developing children³⁰.

Table 4: Comparison of CP economic burden according to comorbid group

Economic Burden/ Comorbid Group	With Comorbid Illness	Without Comorbid Illness	Mann-Whitney U (p) Test
Direct Healthcare Cost (RM)			
Rehabilitation Services	13,941.70	3,357.78	0.322
Alternative Treatment	2,476.60	3,462.22	0.582
Medicine Cost	37.66	44.07	0.781
Purchase of Medical Aid	1,692.45	1,038.52	0.795
Diagnostic Test	127.17	73.33	0.599
Ward Entrance Fee Surgery	35.13	222.22	0.219
Consultation Fee	13.64	242.78	0.267
Total	18,324.35	8,440.92	0.384
Direct Non-Healthcare Cost (RM)			
Transportation Cost	2,400.43	3,150.22	0.062
Accommodation Cost	-	-	-
Total	2,400.43	3,150.22	0.062
Developmental Cost (RM)			
Domestic Helper	1,720.85	2,133.33	0.388
Nursery	222.13	1,280.00	0.024*
Special Education	477.45	493.33	0.477
Dietary Supplement	4,230.66	3,152.00	0.260
Daily Necessities	2,236.75	2,234.67	0.796
Insurance	871.49	1,453.33	0.949
Others	61.40	551.33	0.368
Total	9,820.73	11,297.99	0.406
Indirect Cost (RM)			
Parents and Child Productivity Loss	1,259.73	3,768.80	0.831
Total	1,259.73	3,768.80	0.831
OVERALL TOTAL (RM)	31,805.24	26,657.93	0.317

CONCLUSION

The financial burden experienced by families of children with CP in Malaysia is still less comprehensible and are not addressed properly. Even though the Social Welfare Department provides subsidies to assist in buying support aid, there are still other aspects of needs yet to be addressed. Information about CP economic burden will be able to assist policy makers in planning better services and support to these families based on solid evidence⁷. With the information about types of expenditure needed for providing care for children with CP, the burden shouldered by their parents, it is hoped that policy makers would be able to plan better services and support specifically to address the main burden of these parents. One such service that is glaringly missing is the need for

the establishment of quality early intervention services for these children. Another service which is sorely needed by parents are child care so that they could continue working or opportunities to work from home while caring for their children.

It is hoped that this study would be useful as an important reference to local policy makers, community welfare organizations as well as related non-governmental organisations in providing assistance that are cost-effective for these families and their children. However future research is still needed especially one that includes a bigger and more diverse population. Further investigation is also needed on the impact of job resignation on the QOL and financial situation of parents and families. As such, this paper serves as a sound foundation for future research.

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