

# The Burden Caregiver of Disable Children in Chenderong Balai, Langkap and Tapah

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## Abstract

Caregiver is a person who gives help and protection to someone such as child, an old person, or someone who is sick. Caregiver burden means a high level of stress that may be experienced by people who were caring for another person with some kind of illness. The objectives of this study were to investigate whether the level of burden was affected by the caregiver's gender, to identify the type of children disabilities that affect the level of burden, to identify the difference in child abilities and the level of burden. The reference population was caregiver of disabled children in Perak and our target sample was the caregiver of disabled children in Langkap, Chenderong Balai and Tapah Perak. Cross-sectional research was used for our study and the sampling technique used was stratified sampling. A questionnaire was used to collect our data. Kruskal-Wallis test was used to achieve our hypothesis on income and caregiver's level of burden and the type of children disabilities that affect the caregiver's level of burden while Mann-Whitney U test was used to investigate whether the caregiver's level of burden was affected by the difference in caregiver's gender and the difference on child abilities. The result showed that there were not statistically significant different on median level of burden between the male and female, the income of caregiver and child who has ability and child who does not have ability. The conclusion showed that the median level of burden on income categories were all the same while the median level of burden on type of disabilities was greater for other disabilities and the median of level of burden on child who does not have ability was greater than child who has ability.

**Keywords:** Burden Caregiver, children, disable, Kruskal-Wallis, Mann-Whitney U test

## 1. INTRODUCTION

Caregiver is a person who gives help and protection to someone such as child, an old person, or someone who is sick (Inc.2004) while caregiver burden means by to a high level of stress that may be experienced by people who were caring for another person usually a family member with some kind of illness (Kim, Chang et al. 2012). Lately we have received a lot of news concerning about the disable children that were neglected by their parents. The most popular news was about Muhammad Firdaus Dullah that had been locked up by his own mother (Dali 2014).

His physical was extremely small and thin which was not the size of a normal 15-year-old teen should have with deformed limbs and he could neither walk nor standing assisted. It was really sad to see a teenager in such a state of being neglected. How many of us were shocked by this news? His mother claimed that it was not easy to take care of his son since she was a working mother but we found that would not be a great excuse to leave and lock her own son in the dirty room if she thought to run out of her problem (Singh 2014).

The difficulties of care giving are different depending on the type of their children disabilities. (Kimura and Yamazaki 2013) examined that the level of difficulties of parents are different depend on the difference of their children disabilities. We have discovered many disabilities among children that can be considered as we do our research such as Intellectual Disability (ID), Autism, Down syndrome, Hearing Problem, Speak Disability and Cerebral Palsy (CP). Burden means something that weigh you down, a worry or sadness or a responsibility while caregiver was a person who was taking care and gives help and protection to someone such as a child, an old person or someone who was sick. (Datta, Russell et al. 2002) quoted that (Barnett and Boyce 1995) had given the meaning of burden as recognized medium to erode the family relationship. (Hecht, Graesel et al. 2003) classified somatic symptoms, emotional strains and economic problems as components of the burdens of caregivers. (Datta, Russell et al. 2002) had examined many types of burden like financial burden, burden because of effects on family routine, burden due to effects on family leisure, burden to effects on family interaction, burden caused by the effects on the physical health of other family members and the burden from the effects on the mental health of other family members. The difficulties or level of burden caregiver of disabled children may be different depending on the type of disabilities of the children.

There were many factors influencing the level of burden caregiver of disabled children. One of the factors was the income of the caregiver. (Emerson 2003) stated that the family having an intellectual disability (ID) child tends to economically disadvantaged compared to the family supporting a child that does not have intellectual disability (ID). (Cain and Wicks 2000) found that although financial adequacy or income

become one as the most important factor influencing the level of burden caregiver their report shown that whether the financial was grouped as adequate and inadequate, both groups of caregivers reported mild to moderate burden. However, based on report of (Salama 2012) they stated that caregivers who had inadequate financial experienced more care giving burden compared to others. The caregivers of children with Autism Spectrum Disorder (ASD) experienced more financial burden than caregivers of children with Developmental Disability (DD). (Vohra, Madhavan et al. 2013). (Olsson and Hwang 2001) tested the hypothesis of lower socio-economic status associate to higher depression scores among parents in both families with children with intellectual disability or without intellectual disability and found out that there was no relationship between the socio-economic status and the depression among fathers and mothers with children with disabilities or without disabilities.

Next, the factor that influences the level of burden caregiver of disabled children was the age of the disabled children. According to (Datta, Russell et al. 2002) when there was an increasing in the age of the child, there will also be an increase in burden. They classified that the increase in age of children including their increase in child's physical size. The age of caregiver also contribute to be one of the factors influencing the level of burden caregiver of disabled children. (Cain and Wicks 2000) stated that younger caregivers experiencing higher stress as they gained higher burden scores because they manage more commitments such as career, family and work compared to the caregivers age more than 65 years old.

Furthermore, the education level of caregiver also contributes as a factor associating to the level of burden caregiver of disabled children. Generally, we thought that the caregivers with lower education level may suffer more burdens because they may have less knowledge on care giving skills. However, (Salama 2012) conducted a research and found out that caregivers with lower level of education tend to have higher self-esteem from care giving which lead them to derive less burden of taking care disabled children. Thus, the purpose of this study was to investigate the level of burden of caregiver on disable children.

## 2. METHODOLOGY

The reference population was caregiver of disable children in Perak. The target sample was caregiver of disable children in Langkap, Cenderong Balai and Tapah, Perak.

We did calculate sample size for this study for each variable of interest. We found that the highest sample size was the number of disable children in family by 101 samples. We decide the sample size for our research was 121 after adding 20% of expected missing data. The data was collected at Program Pemulihan Dalam Komuniti (PDK) Tapah, Sekolah Kebangsaan Dato Yahya Suban, Cenderong Balai, Sekolah Kebangsaan Seri Langkap, Langkap, Sekolah Menengah Kebangsaan Sultan Abdullah, Cenderong Balai, and Sekolah Menengah Kebangsaan Dato Sagor, Langkap.

We were using cross-sectional research for this study. This was done by surveying the caregiver opinion at the selected places (Zamalia 2009). The sampling frame was list of all schools that have (PPK & PPKI) and PDK (Pusat Dalam Komuniti) registered at JKM (Jabatan Kebajikan Masyarakat) at Hilir Perak district.

We used stratified sampling for our research. First, we had selected the caregiver in Perak and we decided to find place that have education for the disable children. From the ministry of education website and Jabatan Kebajikan Masyarakat Malaysia website, we decided to choose sample from Program Pemulihan Dalam Komuniti (PDK) Tapah, Sekolah Kebangsaan Dato Yahya Suban, Chenderong Balai, Sekolah Kebangsaan Seri Langkap, Langkap, Sekolah Menengah Kebangsaan Sultan Abdullah, Chenderong Balai, and Sekolah Menengah Kebangsaan Dato Sagor, Langkap.

We used questionnaire as our instrument tool. It was divided into 4 parts where part A was asked about the caregiver's demographic factors. Part B was about particulars of the disabled children such as the disable children age, gender and disabilities. Part C about the abilities of disabled children such as the abilities to eat, go to toilet, take a bath, wearing cloth, sleep, walk and climbing the stairs. Part D was about on the caregiver's emotions such as the caregivers feeling.

The statistical method used were Kruskal-Wallis test to achieve our hypothesis on income and caregiver's level of burden, type of children disabilities affect the caregiver's level of burden and race of caregiver with the caregiver's level of burden. The assumptions for this test were the sample was picked randomly, independent observation, not normally distributed, the variable was numerical and at least the level of measurement was ordinal (Pallant 2010). Mann-Whitney and Bonferroni correction was used to investigate the pair that different to reject the null hypothesis. Bonferroni correction had been used when alpha divide with number of pair. But if Mann-Whitney was conducted the type 1 error was increased but it was able to control if Bonferroni correction was applied. So we tend to accept the null hypothesis and lead to make the wrong conclusion. (Pallant 2010).

The Mann-Whitney U test was used to investigate whether the caregiver's level of burden was affected by the difference in caregiver's gender. The statistical software used do as IBM-SPSS Statistics 21 software package (SPSS 2012).

### 3. RESULTS

We had conducted reliability test to test the validity and reliability of the data collection tools. We used the Cronbach's Alpha test to check the scale's internal consistency. From table 1 we can see that the Cronbach's Alpha is equal to 0.864 is more than 0.8, so there is very good internal consistency reliability for the scale. Hence, we continued collecting our data by distributing the questionnaires to the respondents.

The demographic information about the respondents were collected over a time period of 1 month and from the 119 caregivers surveyed, there were 39(32.8%) male caregiver and the balance 80(67.2%) were female caregiver. Mostly the race for caregiver surveyed were 110(92.4%) Malay, and the others were 5(4.2%) for Chinese, 4(3.4%) for Indian. Furthermore, it was found that the income per month show that 64 of them receive below than RM1000 (53.8%), 46 parents have total income between RM1000-RM3000 (38.7%), 7 parents have total income between RM3001-RM5000 (5.9%). Lastly, 2 parents have total income above than RM5000 (1.7%). In addition, there were 78(65.5%) is the mother of the disable child, 38(31.9%) is the father of the disable children, 1(0.8%) is the brother or sister of the disable child, 1(0.8%) were the grandfather or grandmother of the disable children and there was 1(0.8%) is others that is the aunt of the disable child.

Next, from total of 121 caregivers, 84 of them have male disabled child which contribute to (70.6%) while the rest, 35 (29.40%) have female disabled child. For the grouping of parents, we distributed a questionnaire to ask the parents about their children's disabilities. 64 caregivers (53.8%) stated that their children were having intellectual disability, 18(15.1 %) of the caregiver's children were having down syndrome, 13 (10.9%) were having autism while 4(3.40%) and 3(2.50%) of total 121 respondents' children were having hearing disability and speak disability. The other 5 caregivers (4.10%) indicated that their children were having attention deficit hyperactivity disorder (ADHD) and 13(10.90%) of them were having other type of disabilities which are Cerebral Palsy (CP) and Dyslexia.

After that, we test on the difference between the caregiver's gender and level of burden. Based on table 3 we found that there were not statistically significant different on median level of burden between male and female group since p-value greater than 0.05 (p-value=0.680). Furthermore, we can conclude that the median level of burden on male and female group is equal [median(IQR):14.00(3.00) and median(IQR):14.00(4.00)] respectively. For this test we did check the normality of each group and found that none of the group was normally distributed.

Moreover, we test on the different between the caregiver's income and the level of burden. Based on table 4 we found that there were not statistically significant different on median level of burden between income below RM1000, RM1000- RM3000 and more than RM3001 group since p-value greater than 0.05 (p-value=0.903). Furthermore, we can conclude that the median level of burden on income below RM1000 [median(IQR):14.00(4.00)], Income between RM1000-RM3000 [median(IQR) :14.00(3.00)] and Income more than RM3001 [median(IQR):14.00(6.00)] were the same. For this test we did check the normality of each group and found that none of the group were normally distributed.

We test on the difference between the type of children disabilities and the level of burden. Based on table 4, we found that there were not statistically significant different on the median level of burden between intellectual disabilities, down syndrome, autism and other disabilities since p-value greater than 0.05 (p-value=0.19). Furthermore, we can conclude that the median level of burden on other disabilities [median(IQR) : 15.50(5.00)] is equal with down syndrome [median(IQR) : 15.50(5.00)] that is higher than autism [median(IQR): 14.00(3.00)] and intellectual disabilities [median(IQR): 13.50(3.00)]. For this test we did check the normality of each group and found that none of the group were normally distributed.

Finally, we test on the relationship between child abilities and the level of burden. Based on table 3 below, we found out that there was significant difference on median level of burden between child who has ability and child who does not have ability since p-value was smaller than  $\alpha=0.001$  (p-value = 0.000). However, there was a difference in median level of burden on child who has ability and child who does not have ability which shown that the level of burden for caregiver of child who does not have ability was higher [median (IQR): 16.00 (3)] than the level of burden for caregiver of child who has ability [median (IQR): 14.00 (2)]. For this test we did check the normality of each group and found that none of the group were normally distributed.

### 4. DISCUSSION

The characteristics of caregivers also affect our results because most of the Malay respondents believe that the children were their responsibility and they felt thankful for having them in their life.

The data presented of the first aspect are totally contra with the previous study which concluded that there is relationship between level of burden of the caregivers and the caregiver's gender (Olsson and Hwang 2001).

The results showed that there is no difference between the income of the caregiver and the level of burden of caregiver. However, the level of burden of caregivers was found the same by the caregivers whose incomes were below RM1000, income between RM1000-RM3000 and income more than RM3000 which

showed that all the caregivers group experienced the same level of burden.

The results also displayed that type of child disabilities did not affect the caregivers level of burden. However, the comparison on median level between the types of child abilities showed that the children with other disabilities which are Cerebral Palsy and Dyslexia scored the highest median which concluded they tend to have highest level of burden.

This is because the children with Cerebral Palsy cannot manage themselves without anyone's help. Most of their daily routines should be done with the help of their caregivers.

Lastly, there is no difference between child abilities and the caregiver's level of burden. The comparison of median on child abilities showed that the total score of child abilities equal to 28 resulted as the highest level of burden to their caregivers. This is because the children with total of abilities score equal to 28 were very dependent on their caregivers in doing their daily routine.

## 5. CONCLUSION

Based on our analysis on data, the effect between gender and level of burden is equal for both genders which are male and female. Next, we can conclude that the median level of burden on income below RM1000, income between RM1000- RM3000 and income above RM3000 are the same. Furthermore, we can say that the median level of burden on type of disabilities is greater for intellectual disabilities (ID) and other disabilities like cerebral palsy, dyslexia, and attention deficit hyperactivity disorder (ADHD), other than autism and down syndrome. Lastly, we can conclude that the median of level of burden on child ability where child that has no ability is higher than the child who has ability.

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Table 1. Reliability Test of the Questionnaire (n=19)

Cronbach's Alpha	0.864
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Table 2. Descriptive statistics of caregiver's survey (N=119)

Variable	n(%)	Mean (SD <sup>a</sup> )
<b>Gender of caregiver</b>		
Male	39(32.8)	
Female	80(67.2)	
<b>Race</b>		
Malay	110(92.4)	
Chinese	5(4.2)	
Indian	4(3.4)	
<b>Relationship of caregiver with the disable children</b>		
Mother	78(65.5)	
Father	38(31.9)	
Brother/sister	1(0.8)	
Grandfather/grandmother	1(0.8)	
Other	1(0.8)	
<b>Income per month</b>		
Below than RM1000	64(53.8)	
RM1000-RM3000	47(38.7)	
RM3001-RM5000	7(5.9)	
Above than RM5000	2(1.7)	
<b>Gender of Child</b>		
Male	84 (70.60)	
Female	35(29.40)	
<b>Type of Disability</b>		
Intellectual Disability	64(53.8)	
Down Syndrome	18(15.1)	
Autism	13(10.9)	
Hearing Disability	4(3.40)	
Speak Disability	3(2.50)	
Attention deficit	4(3.40)	
Hyperactivity		
Disorder (ADHD)		
Others	13(10.90)	

<sup>a</sup>Standard Deviation

Table 3. Comparison on median level burden between male group and female group (n=119)

Variable	Median (IQR)		Z-stat <sup>a</sup>	p-value
	Male	Female		
Level burden	14.00(3.00)	14.00(4.00)	-0.413	0.680
	child who has ability	child who does not have ability		
Level burden	14.00(2.00)	16.00(3.00)	-4.404406	< 0.001

<sup>a</sup>Mann-Whitney Statistics test, IQR: Inter Quartile Range

Table 4. Comparison on median level burden between income and type of children disabilities (n=119)

	n	Median (IQR)	X <sup>2</sup> stat <sup>a</sup> (df)	p-value
<b>Income</b>				
Income below RM1000	64	14.00(4.00)	0.204(2)	0.903
Income between RM1000- RM3000	46	14.00(3.00)		
Income more than RM3000	9	14.00(6.00)		
<b>Type of Children Disabilities</b>				
Intellectual Disabilities (ID)	64	13.50(3.00)	9.975(3)	0.19
Down Syndrome	18	15.50(5.00)		
Autism	13	14.00(3.00)		
Others	24	15.50(5.00)		

<sup>a</sup>Kruskal-Wallis test, IQR: Inter Quartile Range, df: degree of freedom

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