STRESS AND QUALITY OF LIFE AMONG FATHERS OF SPECIAL NEEDS CHILDREN IN KLANG VALLEY

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Abstract

Many research articles have studied the conflicts and stress experienced by parents and mothers of special needs children with different disability such as autism, cerebral palsy, learning disabilities, down syndrome and others. Unfortunately, there are lack of study focusing the experiences of Malaysian fathers of special needs children. This study aimed to examine the stress level using Parental Stress Scale (PSS) and quality of life (QOL) using WHOQOL-BREF, a short version of QOL and to study correlation between stress and quality of life. Two hundred and fifty-six (n=256) samples included fathers of special needs children (n=128) and fathers of typical children (n=128) were recruited into this cross-sectional study from centers or schools in Klang Valley. A set of questionnaire containing 3 sections were distributed via hard copies and online survey. Section 1 comprised father's demographic data and child' demographic data and Section 2 was a questionnaire Parental Stress Scale (PSS) to assess stress of fathers and Section 3 was WHOQOL-BREF questionnaire to examine the quality of life of fathers. The demographic data, PSS score and WHOQOL score was analysed using descriptive analysis. Meanwhile, Pearson r was used to identify the correlation between stress and quality of life of fathers of special needs children. The findings of the study showcased that fathers of special needs children have higher mean stress level (M=44.50) and lower quality of life (M=14.16) and where else, fathers of typical children has lower stress level (M=39.70) and higher quality of life (M=15.41). The Person r correlation test indicated moderate negative correlation between stress and quality of life (QOL) of fathers of special needs children, r= .328, p<0.01, two-tailed, n=128. Higher parental stress indicated lower level of sensitivity and poorer quality of parental-child relationship.

Keywords: Stress, quality of life, father, special need children, parental stress.

INTRODUCTION

Traditionally, fathers are absent from the child-rearing (Carpenter & Towers, 2008). Fathers in Asia, including Malaysia, are seen as holding more power over wife and family, authority, some patriarchal than Western, main decision maker in a family and superior than his wife (Hirschman, 2016; Tseng & Verklan, 2008). Fathers are seen to have more engaged actively in family now but mothers are still seen as having caregiving obligations (Tseng & Verklan, 2008). Fathers plays numerous and multiple familial roles, duties and responsibilities and they are getting more involved now compared to before (Yogman & Garfield, 2016). In fact, fathers have profound roles in making differences in their children's life and family functioning (Nicholas, 2013). Contemporary, there was shifting of perspectives of fatherhood from detached to more recent as involved, integral to well-being of family (Nicholas, 2013) as there are evidence also as more women going to workforce, fathers are more involved with children and share household tasks and child care as well (Yogman & Garfield, 2016). Fathers are also playing important roles in the relationship of mothers, siblings and in the family. The perspectives about the role of fathers, social expectation and diversity of culture is wide.

Studies have also shown that having disabled child such as physical disabilities are associated with higher risk of poor mental health issues (Hung, Wu, Chiang, Wu, & Yeh, 2010). Parents of special needs children such as autism have more work-family conflict issue (Sitimin, Fikry, Ismail, & Hussein, 2017) A study showed that fathers with special needs experience higher physical and psychological stress and this affects health and QOL of fathers (Darling, Senatore, & Strachan, 2012; Huang, Chang, Chi, & Lai, 2014). Both internationally and locally on the stress levels of parental and mothers of special needs children are documented (Shin & Nhan, 2009; AlHorany et al., 2013; Miskam, Rumaya Juhari, 2017; Ilias et al., 2017) which have focused more on experience of parents. The western based studies may present some universal similarities of experiences but it may not reflect the total experience of fathers of special needs children in Asian society, including Malaysia, because fathering is affected by social construct and cultural ideas, social expectation (Olmstead et al., 2009). Western and Asian cultures are indeed different. However, there is a little published studies that only specifically study about stress and QOL of fathers but instead parents or mothers that can be found in Malaysia (Wati Nikmat, Ahmad, Lai Oon, & Razali, 2008; Vetrayan, Jayachandran; Daud, Azmah; Victor PaulRaj, 2013; Narkunam, Hashim, Sachdev, Pillai, & Ng, 2014; Kamaruddin & Mamat, 2015). Therefore, this showed the necessity to conduct study that focus on investigating stress and QOL of Malaysian fathers of special needs and typical children. Studies have shown fathers of special needs children have a difficult time with life and higher stress, not able to effectively cope which related to lower life satisfaction (Darling et al., 2012).

Research methodology

A cross-sectional, retrospective study was used to investigate the stress level and quality of life of fathers of special needs children and typical children. A purposive sampling was used because of characteristics of the population which was specific gender, fathers and centres were recruited for a specific purpose according to the aim of study. One hundred and four kindergartens, primary schools, special needs centres, schools and autisms centres, down syndrome centres, rehabilitation centres or any centres in Klang Valley including Kuala Lumpur and some districts of Selangor were contacted and requested permission for conducting study in their organization. The centres which agreed to participate in the study, consent approvals with response letter were obtained from the centres and explanation about the study was given to them. A formal letter, support documents, consent forms and survey forms were given to the targeted centres. These documents have sent out to the relevant subjects to request for permission. Participants were also enrolled online from Facebook groups, special needs fathers group, parental group and others. The response rate of the survey was about 30.6 % by online or hard copy returned the questionnaires. Out of 398 participants, 74 were excluded due to incomplete questionnaires. The rest of 324 is downsized to the sample size of 256, comprised of 128 fathers of special needs children (n=128) and 128 fathers of typical children (n=128) were analysed in the study. Before selection of the participants, they were identified if they met the inclusion criteria of the study. The inclusion criteria of the study were Malaysian father of children with special needs and/or typical children, who has child/children less than 18 years of age. The exclusion criteria were non-Malaysian citizens and have any severe or chronic medical conditions that affect cognitive and psychosocial level (e.g: Metastatic cancer, cerebrovascular disease, severe traumatic brain injury, severe Diabetes Mellitus, neurocognitive disorder, severe mental illness, etc.)

Instruments & data analysis

Section 1 comprised of father's demographic data and child' demographic data and Section 2 was a questionnaire Parental Stress Scale (PSS) to assess stress levels of fathers and Section 3 was WHOQOL-BREF questionnaire to examine the quality of life of fathers. The demographic data, PSS score and WHOQOL score was analysed using descriptive analysed. The data was checked normal with QQ plot, kurtosis and skewedness. The skewness of this distribution are fairly symmetrical. Although kurtosis is less than 3 which is supposed to be normal distribution, but the risk of underestimation of variance would be reduced with a larger sample size of more than 200++ (Tabachnick & Fidell, 2016). The distribution is also assumed to be normal and thus, parametric test was used. Meanwhile, correlative analysis such as Pearson r was used to identify the correlation between stress and quality of life of fathers of special needs children and typical children.

Ethical consideration

Ethical clearance and consent were obtained from Perdana University Institutional Review Board (PU- IRB) and approved with IRB ID of PU IRBHR0231. All the personal demographic information had kept privately and confidentiality.

Results

Prevalence of socio-demographic data, parental stress and QOL

A sample of fathers of special needs children (n=128) and fathers of typical children (n=128) were recruited and data was analysed. The age of the participants was categorised into three groups according to adult life stages (Medley, 1980). Majority of the father participants (n=141, 55.1%) were early middle age between 35 to 44 years old and later followed by late middle age (n=64, 25.0%) and early adulthood (n=51, 19.9%) as delineated in Table 1. The mean age of fathers is 40.04 years old (SD 7.010).

Majority of the participants were Malays (n= 125, 48.8%) and followed by second-largest population which is Chinese (n=107, 41.8 %) and Indians and others. Majority of participants were (n=125, 48.4%), Buddhists (n=77, 30.1%), Christian (n=30, 11.7%) and Hindus (n=18, 7.0%) and others (n=6, 2.3%). Majority father's participants were still married (n=376, 98.7%). Majority of the fathers pursued tertiary education (75.1%) while 22.0% of fathers completed his secondary education.

Almost half of the fathers working in the private sector (n=123, 48.0%). The average working hours of fathers in total is 9.102 hours (SD .197). Forty-nine point six percent (49.6%) of fathers working about 8.1 to 12 hours (n=127), followed by 43.0% fathers reported working about 4.1 to 8 hours as shown and 3.5% (n=9) fathers reported working more than 12 hours as shown in Table 1. Highest gross monthly household income group is the middle aged group (M40) RM 3 860- RM 8319 which is about 44.9 % (n=115), followed by above RM 8319 (n=78, 30.5%) and < RM3860 (n=63, 24.6%).

Most of the participants reported having 2 children (n=105, 41.0%). The least number reported by fathers (n=17, 6.6%) that they are the only main caretaker of their children but instead 66.4% which is more than half of the fathers reported that both him and wife are the main caretaker (n=170). The following main caretaker will be wife (n=40, 15.6 %) and others (n=29, 11.%). Most of the fathers with special needs children (n=113, 44.1%) reported they have 1 special needs child.

Table 1: Demographic background of fathers

Variables	Frequency (*f*)	Percentage (%)
Father with special needs child(ren)	128	50.0
Father with typical child(ren)	128	50.0
Total	256	100
Age		
23-34 (Early adulthood)	51	19.9
35-44 (Early middle age)	141	55.1
45 and above - 62 (Late middle age)	64	25.0
Total	256	100.0
Race		
Chinese	107	41.8
Malay	125	48.8
Indian	20	7.8
Others	4	1.6
Total	256	100.0
Religion		
Muslim	125	48.4
Christian	30	11.7
Hindu	18	7.0
Buddhism	77	30.1
Others	6	2.3
Total	256	100.0
Marital status		
Single	0	0
Married	254	99.2
Divorced	1	.4
Separated	1	.4
Total	256	100.0

Level of education		
Primary	3	1.2
Secondary	59	23.0
Tertiary education (Form 6, Diploma and above)	194	75.8
Total	256	100.0
Occupation		
Unpaid worker/Homemaker	0	0
Self-employed	78	30.5
Government/Semi-government Sector	47	18.4
Private Sector	123	48.0
Unemployed	8	3.1
Total	256	100.0
Working hours in a day		
N/A	8	3.1
1.0-4.0	2	.8
4.1-8.0	110	43.0
8.1-12.0	127	49.6
>12.0	9	3.5
Monthly household income		
< RM3860	63	24.6
RM 3 860- RM 8319	115	44.9
above RM 8319	78	30.5
Total	256	100.0
Number of children		
1	64	25.0
2	105	41.0
3	55	21.5
4	24	9.4
5	7	2.7
>5	1	0.4
Total	256	100.0
Main caretaker		
My wife and me	170	66.4
Myself	17	6.6
Wife	40	15.6
Others(family members/maid/relative/babysitter/etc)	29	11.3
Total	256	100.0
Number of special needs child (ren)		
0	128	50.0
1	113	44.1
2	13	5.1
>2	2	.8
Total	256	100.0
Presence of ill		
Without ill	236	92.2
With ill	20	7.8
Total	256	100.0

Stress levels of fathers

Table 2 showed the means of fathers, analysed descriptively. According to the means of fathers, the fathers with special needs children are having increase in means of stress level than fathers with typical children. The mean of the stress of fathers with special needs children (44.50) is higher than the mean of stress level of fathers with typical children (39.70). As indicated by interpretations Parental Stress Scale (PSS), fathers with special needs children which have higher stress level has lower levels of sensitivity to their children, poorer child behaviours and lower quality of parent–child relationship compared to fathers with typical children. Where else, as the mean of stress level of fathers of typical children is lower and this indicated better level of sensitivity to their children and better quality of parent- child relationship.

Table 2: Stress level of fathers

Stress Level	**Mean**	Min	Max	**Skewness (SE)**	**Kurtosis (SE)**
Fathers with special needs children	44.50 (9.787)	24.00	76.00	.695 (.214)	1.019 (.425)
Fathers with typical children	39.70 (8.50)	23.00	60.00	0.153 (.214)	-.629 (.425)

*Significant value, α= 0.05

Table 3: QOL of fathers

Quality of Life	**Mean (SD)**	**Min**	**Max**	**Skewness (SE)**	**Kurtosis (SE)**
Overall Quality of Life					
• Fathers with special needs children	14.16(2.604)	8.00	20.00	-.386 (.214)	.071(.425)
• Fathers with typical children	15.41 (2.625)	8.00	20.00	.219 (.214)	-.122 (.425)
Domain 1: Physical health domain Quality of Life					
• Fathers with special needs children	12.38(1.722)	7.43	16.57	-.209 (.214)	.344(.425)
• Fathers with typical children	13.31(2.006)	8.00	19.43	.429(.214)	.375(.425)
Domain 2: : Psychological component of Quality of life					
• Fathers with special needs children	13.44(1.883)	9.33	19.33	.267(.214)	-.425(9.33)
• Fathers with typical children	14.49 (1.945)	10.00	20.00	.391(.214)	.166(.425)

Domain 3: Social relationship component of Quality of life					
• Fathers with special needs children	14.25(2.712)	6.67	20.00	-.547 (.214)	.406(.425)
• Fathers with typical children	15.26(2.834)	8.00	20.00	-.321(.214)	-.286(.425)
Domain 4: Environment component of Quality of life					
• Fathers with special needs children	13.82(2.109)	8.50	19.50	-.206(.214)	-.343(.425)
• Fathers with typical children	14.82(2.403)	9.50	20.00	.326(.214)	-.336(.425)

Quality of life of fathers

As shown in Table 3, the overall mean of QOL of fathers with special needs children (14.16, SD=2.604) is lower and the QOL of fathers with typical children is higher. It showed that the following domains 1 to 4 which are physical health, psychological, social relationship and environment components of QOL aspects for father with special needs children are lower.

Correlations between parental stress and QOL

Table 4 showed Pearson r indicated the evidence of a statistically significant bivariate association between stress level and QOL. It indicated in the table 13 the presence of a moderate linear negative correlation between the level of stress and an overall total of QOL, r = .328, p<0.01, two-tailed, n =128. A negative (inverse) correlation means the stress level is inversely proportional to the QOL. This moderate, negative correlation between two variables with high parental stress scale, lower QOL of fathers of special needs children. Other than that, the Pearson r indicated that the presence of moderate, negative correlation between the level of stress and all the other domains, r = -.319 (physical health domains), r = -.356 (psychological domain), r =-.351 (social relationship), r = -.309 (environment domains), p<0.01, two-tailed, n=128. Among these domains, the highest strength of the correlation is between stress level and psychological domain.

Table 4: Correlation between stress level and quality of life of fathers of special needs children

Variables	**Stress**		
Quality of life	**N**	**Sig.(2-tailed)**	***r***
Overall Quality of life	*128*	*Less than 0.01***	*-.328*
Physical Health of Quality of life	*128*	*Less than 0.01***	*-.319*
Psychological domain of Quality of life	*128*	*Less than 0.01***	*-.356*

Social relationship domain of Quality of life	*128*	*Less than 0.01***	*-.351*
Environment domain of Quality of life	*128*	*Less than 0.01***	*-.309*

r= correlation coefficient, **Correlation is significant at the 0.01 level (2-tailed). **

Discussion & Conclusion

To the best of our knowledge, this study is the few studies that focused on studies about stress and quality of life of fathers. Malaysia is a multi- ethnic country which comprises with the 3 main groups with Malays form the majority and majority of the participants were Malays and Muslims.

In this study, the mean of the stress of fathers with special needs children is higher and the mean of stress level of fathers with typical children is lower. The higher parental stress can indicate low levels of parental sensitivity to their children, poorer child behaviour and lower quality of parent- child relationship. This can also mean that fathers of typical children have better sensitivity and quality of parent- child relationship as compared to fathers of special needs children. Our study is consistent with the findings of previous studies regarding parental stress of fathers of children with special needs such as autism were significantly higher than parental stress of fathers of typical developing children (Dabrowska & Pisula, 2010; Darling et al., 2012; Huang et al., 2014; Narkunam et al., 2014; Nadeem, 2016). We postulated that fathers of children with disabilities experienced has greater stress in daily parenting, lower level of coping compared to fathers without disabilities who have a higher level of coping (Darling et al., 2012). Fathers of special needs children experienced intense daily routine and events and their children required more assistance in task completions and multiple and evolving treatments services. Fathers experienced more stress in financial burden, flexible time and responsibility (Nadeem, 2016).

Our present study's findings showed the overall mean of QOL of fathers with special needs children is lower than the QOL of fathers with typical children even the physical health, psychological, social relationship and environment domains of QOL is also lower in fathers of special needs children compared to fathers of typical children. Similarly, quality of life health-related QOL of parents of children with such as autism spectrum disorder, ADHD, cerebral palsy (CP), speech and hearing impairment showed that the parents had lower levels of HRQOL than parents of typical children (Benjak, Mavrinac, & Šimetin, 2009; Xiang, Luk, & Lai, 2009; Johnson, Frenn, Feetham, & Simpson, 2011; Guillamón et al., 2013; Aras et al., 2014; Huang et al., 2014). Having special needs child has direct effect or parental strain has indirect effect to lower health- related mental health-related quality of life (HRQOL) (Huang et al., 2014). However, having children with developmental disabilities does not directly effect on physical health related but instead induced high perceived parental strain and dissatisfaction. The factors of impact of having children with special needs on the QOL are the influence of socio demographic factor, child related disability factor and psychosocial variables such as parenting stress can be the mediating factors affects the QOL. Health professionals should screen the fathers' stress and HRQOL when raising up special needs children as this will affect not only the fathers mental HRQOL but the child as well. In a study (Davis, Davis, Freed, & Clark, 2011), fathers who are depressed are more likely to report spanking their 1-year-old child compared to fathers who are not depressed.

In present study, our findings showed that negative correlation between the stress level and an overall and domains of QOL of fathers of special needs children. It means higher parent stress indicated low levels of sensitivity to their children and lower quality of parent–child relationship is correlated to low fathers' QOL. The current findings are consistent to previous study that negative correlation between stress and QOL of parents of special needs children such as in Developmental disabilities and Thalassemia (Huang et al., 2014; Miskam & Juhari & Yaacob, 2017). However, parental stress induced has indirect effects on the decrease in physical component of HRQOL of fathers but not due to have children of special needs children (Huang et al., 2014). Parental strain is induced due to the demands of daily care of children which requires fathers to spend time at hospital for the child's treatment and at home and then their leisure and personal interest engagement is limited due to no time (Berry & Jones, 1995; Lv et al., 2009; Huang, Chen, & Tsai, 2012). In Huang et al. (2014), it provided the explanation that the children's disability not severe enough, fathers still able to handle the daily activities of the children. Secondly, the severity of the disability of the children is not enough to affect the physical health of fathers. Thirdly, younger fathers of disabled children have no direct impact by the disability of the children on physical health related. High exposure of perceived stress has indirect effect to physical HRQOL and it can reduce immunity. Parental stress can also partially mediate the relationship of having children with special needs and mental HRQOL has showed the fact that both parental stress and also the having children with disabilities impacting on paternal mental HRQOL (Huang et al., 2014). Thus, a multiple groups of health professionals who

treat their children should detect earlier, aware and give stress reduction intervention to fathers of special needs children to ensure improvement of physical health. Darling et al. (2012) mentioned that fathers of special needs children have problem parenting stress, their ineffective coping and physical or psychological health reactions were related to the satisfaction with life. Thus, suggestions of coping styles should be advised to fathers to manage stress. Psychological acceptance can help to alleviate the stress and cognitive behaviour therapy able to help the fathers of special needs children (Singh et al., 2007; MacDonald, Hastings, & Fitzsimons, 2010). Support group and peer support model allow for more engagement so that fathers can discuss the personal challenges in rearing a child with a disability.

In conclusion, the findings showed fathers of special needs children have higher stress, lower overall and physical health, psychological, social relationship and environmental QOL compared to fathers of typical children and parental stress is correlated with the QOL. Although fathers of special needs children showed higher mean of stress levels and lower mean of QOL than fathers of typical children in a descriptive way, no statistical tests used to identify the significance differences. Therefore, it is suggested to use statistical tests to confirm and infer the findings statistically However, it limits the ability to infer causal relations due to this is a cross sectional study. Further research is suggested to use longitudinal studies to suggest cause and effect relationship of stress and effect. Other limitations of the study such as faced response bias of reporting about perception of disability, and thus, it is recommended to only recruit those who received confirmed diagnoses. Several confounding factors will affect study and thus, it is suggested to limit by stating inclusion and exclusion criteria for each group clearly. Next, small sample size is unfair to generalise the findings of the study to the whole Klang Valley population. Again further research is recommended with a bigger sample size. However, hopefully this study benefits the fathers, families, community and possibly create awareness in the society. Malaysian government can come up more resources for the special needs population and who knows could be the serving as protective factors against stress for them.

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