

Comparison of Health-Related Quality of Life (HRQoL) and Family Functioning between Caregivers of Children with Autism Spectrum Disorder (ASD) in Urban and Rural Areas

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Keywords:

Autism spectrum disorder, family functioning, health related quality life (HRQoL), urban areas, rural areas

ABSTRACT

Autism spectrum disorder (ASD) is a developmental disability that can lead to substantial social, communication, and behavioral difficulties. Challenges in caring for a child diagnosed with ASD impact the caregiver's health-related quality of life (HRQoL), family functioning and total family impact. The quality of life in individuals varies depending on living areas as living standards in rural areas are not the same as in urban areas. However, only a few researchers make detailed studies about disabled children's families in rural areas. The findings that used samples which only represented the families of children with ASD in urban areas might have restricted generalization to those families residing in rural areas who cannot access professional service. Thus, this study is conducted to compare the HRQoL and family functioning as well the total family impact as a whole among caregivers of autistic children who are living in rural and urban areas. A total of 112 caregivers who send their autistic children to special education integrated program (SEIP) in Selangor, Malaysia, was participated in this study. The research instrument used was the Malay Version of the PedsQL Family Impact Module. An independent t-test was run to identify any significant difference between living areas (urban, rural) and family impact scores (Total Impact, Parent HRQoL Summary, and Family Functioning Summary) among the participants. The mean difference between both living areas for HRQoL Summary Score of the parents/caregivers, Family Functioning Summary Score, and Total Impact Score was 1.52, 1.31, and 2.63, respectively. It revealed that both populations were impacted by their autistic children. However, there is no significant difference between living areas and all the family impact scores among caregivers of children with ASD. This study emphasizes the provision of support and help must be given to both populations equally but must fit the populations' needs.



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1. INTRODUCTION

Autism spectrum disorder (ASD) is known as a set of neurodevelopmental conditions that are highly heterogeneous in which semantically and medically clustered as they share mutual behavior, including poor communication skills, unusual social interactions, and also behavior that are commonly repetitive or stereotypical [40]. World Health Organization (WHO) has estimated that in every 160 children in this world, one child will be diagnosed with ASD [55]. Based on the National Institute of Mental Health, boys are more common with ASD (3.0%) compared to girls (0.7%), and it occurs regardless of what kind of racial and ethnic types [35]. In Malaysia, the statistics of ASD rise every year, and concerning the analysis of the national gross birth rate per year, almost 8,000 to 9,000 babies born tend to have autism [33]. Difficulties in caring for a child diagnosed with autism which has a problem in sleep and behavioral dysregulation [30], might impact the caregiver's quality of life in many ways [23]. In caring for children with a severe level of ASD, there is a more significant burden in terms of economic aspects, and the families will be significantly impacted as they need to be responsible for the high demands of caregiving [26]. Having a disabled kid not only increases stress and giving more burden to parents in finding adequate and inexpensive childcare, but also reflect the negative impact on the mental and physical health of the caregiver, and influences decisions regarding career, education/training, and having other children [43]. It is parallel to the finding made by, where it discloses that caregiving of a disabled child is associated with poor health-related quality of life (HRQoL) in dimensions of both physical and mental health of parents [52]. The term health-related quality of life (HRQoL) refers to the statement that the most valued aspects of life are related to health [13]. HRQoL theory in this study was explained by using the second type of quality of life model in research [47]. The model described that quality of life could be evaluative using a predefined set of different dimensions that apply to all people. According to previous WHO definitions, these dimensions are related to the aspects of physical, psychological, and social well-being [47]. Various factors that could influence a dimension of the whole status and well-being to signify and represent the meaning of quality of life [48]. Lower quality of life is associated with depression, anxiety, and any other conditions [18]. A significant stress that comes from parenting and caring for a disabled child such as ASD may affect the HRQoL of the entire family [17]. From the research conducted, parental distress is strongly associated with psychological, physical, social, and environmental HRQoL in the caregiving of autistic children [50]. Besides, financial status, support from others, and career were also categorized as domains with lower results in terms of satisfaction with the family quality of life, leading to a poor outcome [48]. The children's behavior problems that contribute to parental stress and family functioning also need to be addressed [42].

Besides affecting the quality of life, it is also found that parents of children with severe autistic behaviors reported higher levels of parental stress and lower levels of family functioning than parents of children with less severe ASD and typical children [25]. Family functioning is an essential source of family support [20] and, factors such as family structures, family member's relationship, family stage, life events, family's economic and social status, are capable of influencing the family functioning [8]. The more significant difficulties in family functioning also have been associated with minimized use of adaptive coping and lower social support [22]. Aspects such as family cohesion, family flexibility, parent-child relationships, family conflict, and family problem-solving abilities have all been lacking in families with children with chronic illnesses [31]. Moreover, parents of autistic children are more stressed and vulnerable to adverse outcomes than parents of other disabilities [10], and it was signaled that there is a high prevalence of stress and a psychological disturbance experienced by autistic children's parents [37]. Families with special health care need children have been identified to receive more burden care stemming from both differences in socioeconomic and health systems [49]. In a study by researchers found that living standards in rural areas are not the same as in urban areas, as there is a gap between them [46]. The level of quality of life in individuals varies depending on the living areas, and the finding shows that lower scores of subjects' quality

of life in rural areas may be according to the psychological distress that subjects faced [36]. It is challenging to get access to any services in rural areas, and also, there is limited existing support along with increases in financial burden issues [14]. Despite the government's best attempts to give access to modern healthcare, factors such as rural poverty, ignorance, behavior, culture, and women's status have had a negative impact on the usage of rural healthcare [5]. However, even though it is obvious the environment between urban and rural has differences, a study conducted by showed that the urban populations dominate a higher level of depression compared to the rural populations [45].

An urban area is classified as a well-developed region surrounded by a city [34]. Primary caregivers with autistic children who are registered with West Virginia Autism Training Center located in Huntington city had low marks in health-related quality of life (HRQoL) scores which differ from the general population, and it was indicated that there are different contributing factors affect the mental and physical HRQoL of the caregivers [22]. Same with one a research conducted in Milwaukee and neighboring counties, the finding highlighted the mental HRQoL of the mother with children with autism spectrum disorder (ASD) is lower when compared with the general population, and it is recommended for an occupational therapist to make a psychosocial screening and referral for this group [44]. It is stated that the means that influence the mental HRQoL of the caregivers was the care recipient level of functional impairment, the use of maladaptive coping approach, and also burden that the caregivers need to carry, while factors that negatively impact the physical HRQoL of the caregivers was the care recipient extent of behavioral problems and the lack of support from social context to the caregivers [22]. A study conducted in Baghdad city concluded that mothers of autistic children, when compared to fathers, have deficient levels of environmental comfort as well as psychological and physical well-being [9]. However, both caregivers' quality of life is reported at a moderate level, requiring more attention and support [9].

In the study that was conducted in Michigan, during periods of crisis, mothers were more inclined to tell that the family was seeking social help and that mothers received substantially more social support from their friends and family compared to fathers yet, most of the subjects in the research were satisfied with the functioning of the family [4]. It is found that the mothers of children with ASD required more assistance, and some married mothers in the current study did not feel supported by their partner/husband and families [21]. The population in rural areas is few compared to urban, and a rural area is defined as an open land that has not many homes or building structures [34]. Carried out research in two different areas, which are in Arkansas and New York [24]. Arkansas is one of the rural states, while New York is known as an urban state. It is reported that parents with autistic children from Arkansas have less burden of caregiving yet experienced more happiness compared to parents from New York. These results might be because of the availability of resources such as informal care, which make the difference between economic and cultural in both locations. Nonetheless, other parents' HRQoL scores have no significant differences in both types of parents [24].

Also have done a study that compares the quality of life of parents with autistic kids who lived in two different regions [39]. Not only quality of life, stress, and applied coping mechanisms of the parents also have been measured. The results revealed that the parents who came from areas with low population density were closed with a coping strategy of avoidant, which is entirely different from parents who lived in highly populated regions. Surprisingly, the quality of life, stress, and daily routine of parents for both parts have no different however, it indicates that samples from both areas faced higher stress levels associated with low quality of life, which is worse than parents with typical children [39]. Family adaptability is one criterion of family functioning [27]. Behavioral problems contribute to not only parental stress but also family functioning [42]. One study conducted by revealed that families who carry responsibilities in caregiving of

children with a behavioral problem in rural areas got a poor score in family adaptability than families in urban areas [53]. The authors also reported the rating discrepancies for family functioning by the parents correlated with the residential areas, and the data analysis indicated that parents in urban areas showed a more significant disparity than those in rural areas.

There are 300,000 people with autism spectrum disorder in Malaysia and the deficiency of access to the facilities and services of health for affected parents who want to seek an early diagnosis for their children, especially in rural areas, remains a big issue [41]. ASD has been shown to influence family functioning and quality of life negatively, and many parents of children with ASD are left to coordinate their child's care with little continuous help and education [32]. Most of the autistic children's parents were found to experience some issues regarding the impact of time, emotional, developmental, and financial burdens that affect their quality of life [29]. Children with ASD would affect the family system and family functioning as the family will suffer from the implications when parents are overloaded with their ASD child's behavioral issues [19]. Even though the improvement of the health of 'disadvantaged' rural communities, particularly the rural poor, women, babies, children, and the disabled, has been a top concern for healthcare professionals, yet the disparities in health status between urban and rural populations continue to exist [5].

Even though autism is becoming more familiar, the services for the patient are still limited in rural areas, and public awareness about ASD must rise to fulfill the demand for enough services and support [3]. People in rural sites have lower opportunities to access health care facilities [5]. Meeting the healthcare demands of rural residents with disabilities will necessitate interventions beyond healthcare, such as transportation and access concerns in general [28]. Compared to urban areas, many developmental programs are established, and various public facilities such as hospitals, health centers, education centers, and others are available and maintained to be used by citizens [2]. Studies show that most subjects from rural areas had worse HRQoL scores in which anxiety and depression were more prevalent in rural areas than those from metropolitan areas [36]. It contradicts with the study in which it stated that severe mental illnesses such as major depressive disorder are more common among citizens in urban areas [6]. However, a living standard that includes class disparity, poverty rate, affordable access to quality healthcare, disease incidence, infrastructure, and other factors have been categorized as a poor indicator of the quality of life as it may vary from one person to another [12].

1.1 Survey Point

Only a few researchers make detailed studies about disabled children's families in rural areas [14]. Also stated, the findings which used subjects that only represented the families of children with ASD in urban areas might have restricted generalization to those families residing in rural areas who are unable to access professional service [57], and it may be biased [14]. Thus, the point of this study is to determine the impact of having children with ASD and to compare the HRQoL and family functioning as well as the total family impact as a whole among caregivers of autistic children living in rural and urban areas.

2. Materials and methods

This study was designed based on cross-sectional study and the sampling method used was purposive sampling. Based on the purposive sampling, there is no formula stated to determine the sample size as there is no population data identified since it was challenging to get the data during this pandemic Covid-19. However, based on the purposive sampling's rule of thumb, 50 to 150 respondents are enough to be the samples in this kind of study [11]. For this research study, 161 respondents have been approached, but only 112 respondents (70; urban, 42; rural) were eligible to participate based on the specified criteria. The inclusion criteria for this study are primary caregivers; who have children that were diagnosed with autism

spectrum disorder (ASD), who have 7-12 years old autistic children that school in Special Education Integrated Program (SEIP), Selangor since SEIP has been located in both areas of urban and rural, and who can read and understand in Malay. While the exclusion criteria are caregivers; who are having a severe or chronic medical illness and who have more than one special need children. The instrument used was a demographic form and a validated PedsQL™ Family Impact Module 2.0 questionnaire (Malay Version). The questionnaire has been translated from the original English version. Developed the 36-item parents' self-reported original version to measure pediatric chronic health conditions' impact on parents' health-related quality of life (HRQoL) and family functioning [51]. The purpose of the Malay version PedsQL™ Family Impact Module is to measure the impact of disabled children on the parents' HRQoL and family functioning in a Malaysian context [16]. This module contains 36 questions, including questions in six scales of the questionnaire that reflects parents' self-functioning, which will use in calculating HRQoL summary score except for the scale of communication and worry [1]. It consists of six items of physical functioning five items of emotional functioning, four items of social functioning, five items of cognitive functioning, three communication items, and five worry items. The questionnaire also has two more scales measuring family functioning summary score, which contains three questions of daily family activities and five questions of family relationships. Therefore, besides the summary score of HRQoL and family functioning, the total family impact score can also be gained. All these three scores were classified as family impact scores [16].

The ethical approval for conducting the study was received from the Research Ethics Committee (REC) of Universiti Teknologi MARA (UiTM) in January 2021 thus, the data collection was commenced in January and ended in April 2021. The Google Form link was distributed to the caregivers of children with autism spectrum disorder (ASD) through several social media platforms such as Facebook, Telegram, WhatsApp, and Instagram. Before that, a memo containing the Google Form link, the research title, the research objectives, and the inclusion and exclusion criteria was created. The memo was spread through the caregivers' messenger and posted in groups related to ASD on Facebook and Telegram, such as the 'Autisme Malaysia' group and the 'Disleksia dan Autisme Malaysia (DDAM)' group. Only caregivers who are willing to participate and fulfill the criteria of the study are included. They were informed that the response would only use for study and research purposes.

The process starts with a research proposal and after the ethics has been approved, consents were obtained from the participants. The data were collected through Google Form as it was distributed through social media. This study's data were analyzed using the Statistical Package for the Social Sciences (SPSS) version 25.0. For phase one, a descriptive analysis was performed to obtain frequencies and percentages for categorical data (living area, age, gender and caregiver relationship with the autistic children) in this study. This analysis also was used to determine the mean score and standard deviation of the numerical data, which are caregivers' health-related quality of life (HRQoL) and family functioning. In addition, it was also used to identify the mean score and standard deviation of the total family impact caregivers received from their autistic children. Before that, all the data is computed into the software as this process is vital to ensure the entire data is accurately entered to confirm the findings' validity.

The normality test of Kolmogorov-Smirnov has been executed to determine whether the data is normality distributed or vice versa. For phase two, in order to identify any significant difference between all the dependent variables (HRQoL Summary Score, Family Functioning Summary Score, and Total Impact Score) with the demographic data, which is the living areas of the caregivers (independent variable), the independent t-test (parametric test) was conducted as the data was distributed. Basically, non-significant values of $p > 0.05$ suggest a normal distribution of the data collected, while the significant value of $p < 0.05$

indicates that the data is not normally distributed. If a normal distribution of the data is obtained, a parametric statistical test like an independent t-test will be used in which the mean (standard deviation (SD)) will be applied to determine the distributions (central tendency).

3. Findings and discussion

3.1 Profiles of the caregivers and children with autism spectrum disorder (ASD)

Table 1 shows the sociodemographic profiles of the caregivers of children with autism spectrum disorder (ASD) who participated in this research study. Majority of the caregivers living in urban areas (n = 70, 62.5%) compared to rural areas (n = 42, 37.5%). Most of them are parents (n = 103, 92.0%) with only a few siblings (n = 2, 1.8%) and others (n = 7, 6.3%). Based on table 2, the majority of caregivers have autistic children whose age is around 7-8 years old. Fifty-nine (52.7%) of autistic children were from 7-8 years old, which is higher than the children whose age 9-10 years old (n = 30, 26.85%) and 11-12 years old (n = 23, 20.5%). The children consisted of 89 (79.5%) boys and 23 (20.5%) girls.

Table 1 Sociodemographic characteristics of the caregivers of children with autism spectrum disorder (ASD)

Characteristics	Frequency (n)	Percentage (%)
Living Areas		
Urban	70	62.5
Rural	42	37.5
Relationship to the Children		
Parents	103	92.0
Siblings	2	1.8
Others	7	6.3

Table 2 Sociodemographic characteristics of the caregivers' children with autism spectrum disorder (ASD)

Characteristics	Frequency (n)	Percentage (%)
Age		
7-8	59	52.7
9-10	30	26.8
11-12	23	20.5
Gender		
Boy	89	79.5
Girl	23	20.5

3.2 The Impact of having children with autism spectrum disorder (ASD) on caregivers' health-related quality of life (HRQoL), family functioning and total family impact

Table 3 demonstrates the mean (SD) regarding caregivers with autistic children of each Scales Scores, Parent Health-Related Quality of Life (HRQoL) Summary Score, Family functioning Summary Score and lastly Total Impact Score. Higher scores in these scales signify better HRQoL and family functioning. The mean (SD) of Total Impact Score, Parent HRQoL Summary Score and Family Functioning Summary Score of the caregivers was 70.54 (18.59), 71.43 (18.91) and 72.32 (20.28), respectively. The lowest scale score was the mean score for Daily Activities (mean = 63.02, SD = 24.98), followed by Worry (mean = 63.21, SD = 22.81), Physical Functioning (mean = 69.38, SD = 20.04), Emotional Functioning (mean = 70.89, SD = 21.90) and Communication (mean = 72.10, SD = 24.22). The three highest score in the scale was Family Relationship (mean = 77.90, SD = 20.67), Social Functioning (mean = 73.83, SD = 23.96) and Cognitive Functioning (mean = 72.50, SD = 22.69).

This study shows that the caregivers of children with autism spectrum disorder (ASD) in Selangor have been impacted by their special needs children. It was supported by the data analysis in this study since it was shown that the caregivers had slightly lower results in parent's health-related quality of life (HRQoL), family functioning, and total family impact, yet, very close when compared to the previous study performed in Kelantan, conducted by on caregivers of children with disabilities [16]. However, when compared with caregivers of children with developmental delays in a study made by in Northern Taiwan, the subjects in the current study had higher scores in all three major scales [15]. ASD is a developmental disorder that can result in substantial social, communicative, and behavioral difficulties [7]. Since there are no similar studies were found, the result was compared to the more general studies that used the same instrument as the questionnaire has no cut-off or specific interpretation for the results. However, it may not be fully compatible comparing this recent study's result with both previous studies since the subjects in the research were very general even though caregivers of ASD are one of them.

Table 3 Scores of PedsQL™ Family Impact Module 2.0 among participants

Scale	No. Items	Mean (SD)
Total Impact Score	36	70.54 (18.59)
Parent HRQoL Summary Score	20	71.43 (18.91)
Physical Functioning	6	69.38 (20.04)
Emotional Functioning	5	70.89 (21.90)
Social Functioning	4	73.83 (23.96)
Cognitive Functioning	5	72.50 (22.69)
Communication	3	72.10 (24.22)
Worry	5	63.21 (22.81)
Family Functioning Summary Score	8	72.32 (20.28)
Daily Activities	3	63.02 (24.98)
Family Relationship	5	77.90 (20.67)

3.3 The significant difference between living areas and health-related quality of life (HRQoL) among caregivers of children with autism spectrum disorder (ASD)

Table 4 shows independent sample t-test on the comparison between living areas and health-related quality of life (HRQoL) among caregivers of children with autism spectrum disorder (ASD). Based on the table, the t-test indicated that the total score of HRQoL among caregivers of children with autism spectrum disorder (ASD) in urban areas (mean = 72.00, SD = 20.70) was greater than caregivers in rural areas (mean = 70.48, SD = 15.67) but the score was not statistically significant ($p = 0.682$; 95%CI -5.82, 8.86). The null hypothesis was not rejected since $p\text{-value} > 0.05$, and 95% CI cross 0; thus, there is no significant difference between living areas and HRQoL among caregivers of children with ASD.

There is a gap between living standards in urban and rural areas [46] and usually, the quality of life of an individual will differ based on where the individual resides [36]. However, this study revealed there is no

significant difference between living areas and health-related quality of life (HRQoL) among caregivers of children with autism spectrum disorder (ASD) in Selangor. It means the HRQoL between caregivers of autistic children in urban and rural areas is almost the same since the mean difference was 1.52, which is only a little gap. This result is consistent with a previous study done by, where the quality of life of parents with autistic children in both parts of low and high population density of Western Australia had not much different as it was indicated that both populations faced elevated levels of stress that associated with the level of quality of life [39].

Contrary to a study done by the urban population faced greater depression than those in the rural site [45]. Regarding, even though it was revealed that parents from rural areas of Arkansas experienced less burden in caregiving of autistic children, however, other parents' HRQoL scores showed no significant difference between both parents in Arkansas and New York, which also agreed with the current's data analysis [24]. A living standard has been classified as a poor predictor of life quality because it may vary for everyone [12].

Table 4 Independent sample t-test on the comparison between living areas and health-related quality of life (HRQoL) among caregivers of children with autism spectrum disorder (ASD)

Variables	Mean (SD) of Caregivers in Urban Areas (n=70)	Mean (SD) of Caregivers in Rural Areas (n=42)	Mean Difference (95% CI)	P value
HRQOL	72.00 (20.70)	70.48 (15.67)	1.52 (-5.82, 8.86)	0.682

3.4 The significant difference between living areas and family functioning among caregivers of children with autism spectrum disorder (ASD)

As shown in Table 5, the independent t-test specified that the total score of family functioning among caregivers of children with autism spectrum disorder (ASD) in urban areas (mean = 72.81, SD = 21.65) was higher than caregivers in rural areas (mean = 71.50, SD = 17.97) but the score was not statistically significant ($p = 0.742$; 95%CI -6.57, 9.18). The null hypothesis was not rejected since p -value > 0.05 and 95% CI cross 0; thus, there is no significant difference between living areas and family functioning among caregivers of children with ASD.

A healthy family functioning has been associated with a higher level of support [56]. Highlighted that children's behavior problems contribute to parental stress and family functioning [42], and autistic children typically exhibit challenging behavior such as anger and extreme irritability [38]. It was agreed by since it was found that autism spectrum disorder (ASD) has a negative impact not only on the quality of life but also on family functioning of caregivers [32]. Based on the result, caregivers in this study have been impacted by their autistic children in terms of family functioning. Consistent with a survey completed by, in which it is stated the behavior issue in ASD is related to poor effective family functioning since the caregivers could not experience satisfaction [19].

Nonetheless, it was found in this recent study that the impaction of having children with ASD on caregivers' family functioning had not much discrepancy for the caregivers who live in urban or rural areas of Selangor since the mean difference was only 1.31. The null hypothesis of this research has been accepted. It was stated that there is no significant difference between the living areas and family functioning among caregivers of children with ASD in Selangor. However, it is opposed to the study conducted by where the result suggested that families of children with behavioral problems in rural areas of China have a lower family adaptability score than families residing in urban areas [53]. However, even though the scores may

different, it is not clearly stated about the significant difference as the scores in this study also had difference in mean score. Based on the study, family adaptability is one of the characteristics of family functioning [53], and also stated the same in their research [27]. Besides, parents' rating discrepancies for family functioning were found related to where the subjects lived, and it was shown that couples in rural areas had a greater disparity than couples in metropolitan areas [53].

Table 5 Independent sample t-test on the comparison between living areas and family functioning among caregivers of children with autism spectrum disorder (ASD)

Variables	Mean (SD) of Caregivers in Urban Areas (n=70)	Mean (SD) of Caregivers in Rural Areas (n=42)	Mean Difference (95% CI)	P value
Family Functioning	72.81 (21.65)	71.50 (17.97)	1.31 (-6.57, 9.18)	0.742

3.5 The significant difference between living areas and total family impact among caregivers of children with autism spectrum disorder (ASD)

As portrayed in Table 6, the t-test detailed that the total score of total family impact among caregivers of children with autism spectrum disorder (ASD) in urban areas (mean = 71.53, SD = 20.14) was better than caregivers in rural areas (mean = 68.90, SD = 15.78) and the score was not statistically significant ($p = 0.471$; 95%CI -4.58, 9.84). The null hypothesis was not rejected since $p\text{-value} > 0.05$ and 95% CI cross 0; thus, there is no significant difference between living areas and total family impact among caregivers of children with ASD.

Mentioned that the caregiving of children with a disability might impact the carers and families in many ways [16]. The impaction can also be in the aspect of caregivers' mental and physical health [43], which then affect the health-related quality of life (HRQoL) and family functioning of the parents and caregivers [16]. The result of total family impact or Total Impact Score in this study was the combination of all scales, including the scale of Worry and Communication and the scales in HRQoL and family functioning. In general, the study's analysis exposed that all the autistic children's caregivers who took place in this research have been impacted as a whole in terms of total family impact. Regarding the t-test that has been run, the result showed the mean difference between the Total Impact Score of caregivers in both urban and rural areas was only 2.63.

Thus, it indicated there is no significant difference between living areas and the total family impact among caregivers of autism spectrum disorder (ASD) in Selangor. This research finding was supported by a study performed by where it is stated that the entire families of special needs children who are living in urban and rural areas of Georgia were impacted by their disabled children [54]. The authors added that both group subjects experienced mostly the same issues regarding their child such as social isolation even though there is a difference in the living area which leads to poor in access and availability [53]. It was mentioned by the parents that a child's diagnosis could impact a family by changing a family's life [54].

Table 6 Independent sample t-test on the comparison between living areas and total family impact among caregivers of children with autism spectrum disorder (ASD)

Variables	Mean (SD) of Caregivers in Urban Areas (n=70)	Mean (SD) of Caregivers in Rural Areas (n=42)	Mean Difference (95% CI)	P value

Total Impact Score	71.53 (20.14)	68.90 (15.78)	2.63 (-4.58, 9.84)	0.471
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4. Limitation

There are several constraints in this study. Firstly, the sample population data cannot be reached since it was hard to get the information from the related agency during this pandemic of Covid-19. It affects the calculation of the ideal sample size that needs to be achieved. However, a more general sample size based on the purposive sampling method has been used to cope with the 48 problem. Secondly, the research questionnaire was not able to distribute equally to the targeted participants. One of the inclusion criteria of this study was caregivers who have a seven- to a twelve-year-old child with autism spectrum disorder (ASD) whose send their special need children to a special education integrated program (SEIP) in Selangor. Since all schools in Malaysia, including Selangor, were closed during the pandemic, it was almost impossible to directly contact with SEIP school to help in distributing the questionnaire to the caregivers. The questionnaire just can only be spread through social media and the schools' email, which leads to not so many responses since not everybody has a smartphone or social media or even a time to read the memo about this research. Lastly, the current sample only included caregivers in Selangor state, which cannot be generalized to the caregivers of autistic children in other states since there is a gap between the condition and situation of urban and rural areas in each one of the states. On the other hand, some of the study's limitations may be useful for future research on the same topic.

5. Conclusion

The study delivers critical and vital insights into the impact of children with autism spectrum disorder (ASD) on families in Selangor, Malaysia. It presented evidence suggesting that caregivers of children with ASD have been impacted by their special needs children in the aspect of health-related quality of life (HRQoL), family functioning, and total family impact as a whole. However, according to the findings, the research population's major scores of PedsQL™ Family Impact Module 2.0 were not seriously affected since the mean score was above 70, which is beyond the average. Nevertheless, it cannot be an indicator for people to not take this seriously as the level of caregivers' HRQoL, family functioning, as well as total family impact can be changed with time. If the score's level cannot go beyond the current result in the future, at least the result needs to be maintained. Besides, it revealed there is no significant difference between the living areas of urban and rural areas of Selangor with the aspects of caregivers' HRQoL, family functioning, and total family impact. Even though the result was almost the same for both populations, the provision of support and help must fit the populations' needs and situations since the lacking issue and associated factors contributing to the results in both areas may be different. However, additional studies need to be carried out to identify it as it is a crucial issue since it will impact not only the caregivers' aspect of life but also the children's success in development, rehabilitation, and treatment. The findings in this study could be used to guide future studies. Therefore, the study's results recommend that continuous support must be provided for those with special needs children such as autism spectrum disorder (ASD) without discriminating in which areas they live as both groups of subjects are still impacted. Any initiative's effort must be equal to both populations so that there is no one left behind. Healthcare providers such as occupational therapists should provide various programs such as educational programs to support them. The topic of the educational program can focus on how to cope with autistic children effectively and ways to manage stress in caregiving of autistic children. Besides, it can open many people's eyes like government and non-governmental organizations (NGO) to raise more awareness about ASD to improve the people's understanding of ASD. Thus, more support can be given to those impacted by various parties. This study can also be a baseline to find out specific factors associated with the result. Hence, effective interventions can be specified and made for each population.

Further study about this topic should be done with a more significant number of participants and using probability sampling instead of non-probability sampling so that the result can be generalized for the whole population. It will be much better if the sample size for both populations is equal. Hence, an unbiased result can be produced. The current research study can be one of the ultimate references for those who need related reliable information. Additional research also can be done by comparing caregivers of urban and rural areas in other Malaysia's states like Kedah, Kelantan, and others since there is a gap between each state's urban and rural areas. Further research can also focus on finding out the factors associated with the result of both regions. Even though the current study found that the results for both Selangor areas have no significant difference, the factors may be different for both populations.

6. References

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