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Kertas Asli/*Original Articles*

Psychometric Properties of The Malay Version of The Personal Wellbeing Index: A Preliminary Study Among Caregivers of Children with Autism Spectrum Disorder

(Ciri-ciri Psikometrik Indeks Kesejahteraan Diri Versi Bahasa Melayu: Kajian Awal di Kalangan Penjaga Kanak-Kanak Autisme Spectrum Disorder)

SHOBNAA A/P TINAGARAN, HANIF FARHAN BIN MOHD RASDI, DZALANI BINTI HARUN, KAMARUDDIN BIN HASSAN & SHAHIRAH BINTI MD RASID

ABSTRACT

Caregivers of children with Autism Spectrum Disorder (ASD) can have a compromised quality of life due to caregiving burden and parenting stress. The Personal Wellbeing Index (PWI) is one of the instruments that measure the subjective wellbeing dimension. This study intended to explore this instrument's construct validity and reliability and compare the subjective wellbeing among caregivers based on sociodemographic characteristics. A cross-sectional study was conducted on 53 caregivers of children with ASD recruited from occupational therapy clinics at Hospital Canselor Tuanku Muhriz (HCTM) and the Faculty of Health Sciences, UKM. The PWI has one global life satisfaction construct (1 item) and subjective wellbeing (8 items). The rating scale is anchored from 0 (no satisfaction at all) to 10 (completely satisfied). The statistical analysis indicated that the Malay version of PWI has acceptable unidimensionality (outer loadings >0.5 for all items), convergence validity (Average Variance Extracted (AVE)=0.5781), constructs validity ($r=0.812$, $p<0.001$), and construct reliability ($\rho A=0.8864$, $\rho c=0.9046$, $\alpha=0.8761$). Marital status is significant in achieving life and personal relationships while health issues are significant only in personal health. The Malay version has good construct validity and reliability and can measure the subjective wellbeing of the caregivers of children with autism in Malaysia. The psychometric properties of the PWI Malay version can be further established with a larger sample size. In the future, a national norm of Malaysians' wellbeing could be developed to interpret their wellbeing level.

Keywords: Quality of life; psychometric properties; caregiver; autism spectrum disorder

ABSTRAK

Beban penjagaan dan tekanan keibubapaan boleh memudaratkan kualiti hidup penjaga kepada kanak-kanak dengan Kecelaruan Spektrum Autisme (ASD). Indeks Kesejahteraan Diri (PWI) adalah antara instrumen yang mengukur dimensi subjektif kualiti hidup. Kajian ini bertujuan untuk mengkaji kesahan dan kebolehpercayaan indeks ini dan membandingkan tahap kesejahteraan penjaga kepada kanak-kanak ASD. Sebuah kajian keratan rentas yang merangkumi sebanyak 53 penjaga kepada kanak- kanak ASD yang direkrut dari klinik terapi carakerja Hospital Canselor Tuanku Muhriz dan Fakulti Sains Kesihatan, UKM telah dijalankan. PWI versi Bahasa Melayu mempunyai satu konstruk kepuasan hidup secara umum (1 item) dan konstruk kesejahteraan subjektif (8 item). Skala penilaian bagi setiap item bermula dari 0 (tidak berpuashati) sehingga 10 (sangat berpuashati). Analisis statistik menunjukkan bahawa PWI versi Bahasa Melayu indeks tersebut mempunyai unidimensionaliti yang mencukupi (outer loadings >0.5), kesahan konvergen (Average variance extracted (AVE)=0.5781), kesahan bagi kedua-dua konstruk ($r=0.812$, $p<0.001$) dan kebolehpercayaan konstruk ($\rho A=0.8864$, $\rho c=0.9046$, $\alpha=0.8761$). Status perkahwinan signifikan terhadap domain pencapaian kehidupan dan hubungan peribadi tetapi kondisi kesihatan hanya signifikan pada domain kesihatan diri. Kesimpulanya, PWI versi Bahasa Melayu mempunyai kesahan dan kobolehpercayaan konstruk yang bagus. Oleh itu, indeks ini boleh digunakan untuk mengukur tahap kesejahteraan hidup penjaga kanak-kanak dengan ASD. Ciri-ciri psikometrik indeks boleh dikaji secara terperinci dengan menggunakan saiz sampel yang besar dalam kajian akan datang. Satu norma kesejahteraan bagi warganegara Malaysia boleh dibangunkan supaya tahap kesejahteraan mereka boleh ditafsir.

Kata Kunci: kualiti hidup; ciri-ciri psikometrik; penjaga; kecelaruan spektrum autisme

INTRODUCTION

Caregivers of children with ASD have been reported to experience higher parenting stress and depression symptoms compared to parents of typically developing children (Amireh 2019; Ilias et al. 2018; Lai et al. 2015). Caring for children with ASD also can have significant impacts on family functioning (Gau et al. 2012). According to Higgins et al. (2005), marital happiness, family cohesion, and family adaptability of 66% of the primary caregivers of children with ASD who are never separated or divorced are lower. Besides that, the prevalence of clinical psychological disorders in parents of children with ASD is higher than the estimated global prevalence. In parents of children with ASD, depressive disorders accounted for 31% and anxiety disorders accounted for 33%, which is significantly higher compared to the estimated global prevalence of the general population (Schnabel et al. 2020). Furthermore, Estes et al. (2013) reported that mothers of children with ASD showed significantly higher parenting stress scores than mothers of children in the typically developing children group ($t=-4.62$, $p<0.001$). A statistically significant lower level of subjective quality of life and lower happiness also has been reported by parents of children with ASD compared to parents of non-disabled children (Benjak 2011; Walton et al. 2020).

The World Health Organization defines the quality of life, in the context of the culture and value systems one lives in, as how individuals perceive their position in life regarding their goals, expectations, standards, and concerns (World Health Organization 1997). On the other hand, The Australian Centre on Quality of Life has proposed a different construct in defining quality of life. Knowing that there are two dimensions of quality of life, both objective and subjective, is made of its domain, representing each dimension's entire construct (Australian Centre on Quality of Life 2017). A culturally relevant index of objective wellbeing is used to measure the objective domains. In contrast, satisfaction questions are used to measure the subjective domains (Australian Centre on Quality of Life 2017). Granting everyone the right to decide whether they live a good life has become "subjective wellbeing". This dimension of wellbeing is related to people's evaluations of their lives in affective and cognitive aspects (Diener 2000). Nevertheless, studies were limited to the objective of measuring the quality of life of a parent of children with ASD rather than the subjective measures of the quality of life.

The International Wellbeing Index developed by the International Wellbeing Group in 2001 intended to measure subjective wellbeing based on the respondents' satisfaction on seven life domains (International Wellbeing Group 2013). The developers of PWI adopted the fundamental principle that objective and subjective dimensions are separate entities with little or no relationship to one another. Hence both parameters must be measured separately, which guided them to develop an instrument that could measure the subjective wellbeing of the respondents. PWI-A has been translated into various languages including the Malay language. However, the Malay version has no report on its validity and reliability.

Construct validity measures how well the items selected measure the construct (Sürücü et al. 2020). While convergent validity is the degree to which multiple construct measures that should theoretically be related are related (Gefen et al. 2000). Hence, the various indicators measuring the same concept through convergent validity are assessed to determine whether these indicators converge to measure the underlying construct. This will ensure the uni-dimensionality of the multiple-item constructs and help eliminate any unreliable indicators (Bollen 1989). In contrast, reliability refers to the consistency of a measure. Construct reliability is the extent to which a variable or set of variables is consistent in what it intends to measure (Straub et al. 2004). For example, if the same measuring instrument produces the same results at different times with the same individual, the measuring instrument is reliable.

A common trend can also be observed by studies analysing demographic variables to examine the parents' quality of life of children with ASD. Based on gender, mothers reported more parenting stress, depressive symptoms, daily hassles, life stress, reduced wellbeing, and pronounced caregiving impact on psychological wellbeing (Dabrowska et al. 2010; Nikmat et al. 2008; Phetrasuwan et al. 2009; Quintero et al. 2010). According to Ilias et al. (2017), mothers of children with ASD also reported that caregiving responsibilities negatively affect their overall wellbeing. Besides that, variables such as parents' gender, marital status, education, family income or perceived parental stress were all found to be the predictors of quality of life in families of children with ASD. When combined, family income and parental stress are the two most significant predictors (Hsiao et al. 2018). Furthermore, occupation and demographic variables showed a significant difference in parents psychological wellbeing of parents of children with ASD (Nikmat et al. 2008). However, studies that explore the comparison of wellbeing based on other sociodemographic characteristics of the parents such as race, educational level, marital status, and the number of children with ASD are still lacking. Therefore, this study aims to determine the construct validity and reliability of the PWI in the Malay version and to compare the level of subjective wellbeing among caregivers based on sociodemographic characteristics.

MATERIALS AND METHODS

STUDY DESIGN

A cross-sectional study examining the wellbeing of 53 caregivers of children with ASD. The sample size was derived based on the known population using the Krejcie et al. (1970) formula, with the 5% precision level. Ethical approval for this study was sought from the Research and Innovation Secretariat Universiti Kebangsaan Malaysia with the reference number of JEP-2019-824. Permission was obtained to conduct this study in the Faculty of Health Sciences, Universiti Kebangsaan Malaysia, and Hospital Canselor Tuanku Muhriz (HCTM).

SAMPLES

A non-probabilistic sampling method, which is convenience sampling was used to recruit respondents from caregivers of children with autism. Caregivers taking care of at least one child with ASD, ages 3 to 17 years old, and having family relationships with the child were selected for this study. Caregivers of children with ASD and those with associated physical and sensory disabilities such as auditory and vision problems with autism were excluded from this study. The child's diagnosis of ASD was confirmed by the researcher based on their medical records.

INSTRUMENTS

Two questionnaires were used to collect data for this research including a sociodemographic form and the Malay version of the PWI. The sociodemographic form consisted of respondents' age, gender, race, educational status, marital status, employment status, monthly household income, relationship with the child with ASD, number of children with ASD, and any health issues. The original English version of PWI was translated into Malay known as *Indeks Kesejahteraan* (Australian Centre on Quality of Life 2013). The permission to use the PWI Malay version in this study was granted by the Director of the Australian Centre on Quality of Life (ACQol) and the translators of the Malay version. In addition to that, the Director of ACQol has set no restrictions on using this instrument for teaching, research or practice. The PWI Malay version has one global life satisfaction question and eight items assessing satisfaction with each corresponding to a quality of life domain. The 8th item has been made as an optional item. The eight quality of life domains are: 1) standard of living, 2) personal health, 3) achieving in life, 4) personal relationships, 5) personal safety, 6) community connectedness, 7) future security, and 8) spiritual or religion. Each item consists of an eleven-point rating scale anchored from 0 (no satisfaction at all) to 10 (completely satisfied).

PROCEDURES

Caregivers of a child with ASD were approached in the selected occupational therapy clinics. Caregivers who met the inclusion criteria were then briefed on the study's details. Those who agreed to participate were given a sociodemographic form and a PWI Malay version. Both study instrumentations were attached with an information sheet and consent form. The first 35 respondents were involved in face-to-face data collection. The remaining 18 respondents were approached via google form due to the sudden Covid-19 pandemic outbreak, which led to Movement Restriction Order throughout the nation. The hard copies of the study instruments were transformed into google form and sent through an online platform to the targeted respondents. The data obtained were used to analyse the construct validity and reliability. After establishing the construct validity and reliability of the Malay version of PWI, the satisfaction rating for all the seven wellbeing domains by the caregivers of children with ASD was compared based on sociodemographic characteristics.

STATISTICAL ANALYSIS

Construct validity and reliability of the PWI Malay version were analysed using Advanced Analysis of Composites (ADANCO) version 2.1.1 (Henseler 2017). Specifically, the unidimensionality, convergent validity, and construct reliability of PWI were determined. Unidimensionality was analysed by looking at the outer loading via Confirmatory Factor Analysis (CFA) of each PWI Malay version item on the subjective wellbeing construct. The correlation between subjective wellbeing (eight items) and global life satisfaction was examined via path coefficients. The convergent validity was evaluated based on the Average Variance Extracted (AVE). Three reliability coefficients observed were Dijkstra-Henseler's rho (ρA), Jöreskog's rho (ρc), and Cronbach's alpha (α). The minimum cut-off for reliability of 0.7 and higher is generally recommended (Nunnally et al. 1994).

The IBM SPSS Statistics (Ibm Corp Released 2017) version 25.0 statistical analysis software was used to analyse the second objective of this study. As normality assumptions were violated, non-parametric tests were conducted. The Mann-Whitney *U* and the Kruskal-Wallis One-way ANOVA tests were used to compare satisfaction ratings on PWI quality of life domains based on

sociodemographic characteristics. The median, interquartile range (IQR), effect size (*r*), and significance values (*p*) were reported. Cohen (1988) suggested that the effect size (*r*)= 0.1 as "small", effect size (*r*)= 0.3 as "medium", and effect size (*r*)= 0.5 as "large".

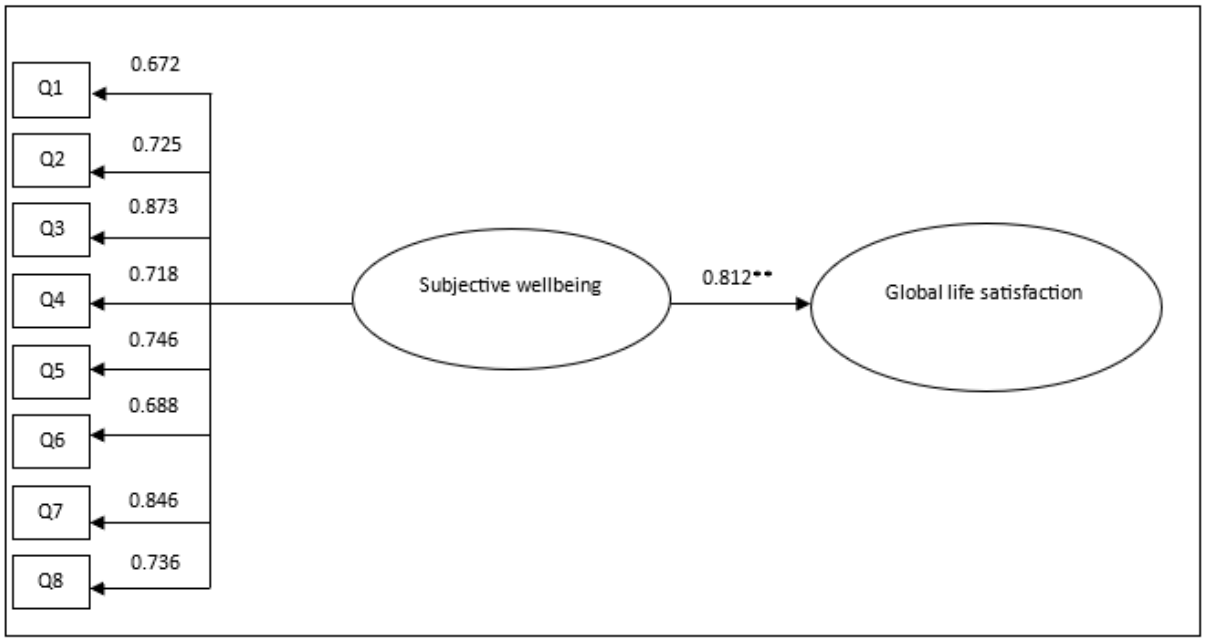
RESULTS

Majority of the caregivers of children with ASD are in their early adulthood age stage (N=31, 58.5%), mothers (N=34, 64.2%), Malay ethnicity (N=47, 88.7%), have a degree (N=17, 32.1%) as the highest educational status, married (N=50, 94.3%), and having one child with autism (N=44, 83.0%). As for employment status, 35 (66.0%) caregivers of children with ASD are working. Besides that, 22 (41.5%) caregivers are categorised under the M40 household income group with a monthly income range of RM 4,360-RM 9,619. Another 45 of the caregivers have no health issues (84.9%) while 8 (15.1%) caregivers have high blood pressure/diabetes/chronic Hepatitis B. The sociodemographic characteristics of the caregivers (N=53) are summarised in Table 1.

TABLE 1. Sociodemographic characteristics of respondents

Variables		Frequency (n)	Percentage (%)
Age	20-40	31	58.5
	41-60	21	39.6
	>61	1	1.9
Gender	Male	19	35.8
	Female	34	64.2
Race	Malay	47	88.7
	Non-Malay	6	11.3
Educational Status	Secondary	12	22.6
	Diploma	15	28.3
	Degree	17	32.1
	Postgraduate	9	17.0
Marital Status	Married	50	94.3
	Not married	3	5.7
Employment status	Working	35	66.0
	Not Working	18	34.0
Monthly Income	B40	19	35.8
	M40	22	41.5
	T20	12	22.6
Relationship with child with ASD	Mother	34	64.2
	Father	19	35.8
Health Issues	No	45	84.9
	Yes	8	15.1
Number of children with ASD	1	44	83.0
	2	7	13.2
	3	2	3.8

The Confirmatory Factor Analysis (CFA) results are illustrated in Figure 1. All items for the PWI Malay version have outer loading values of >0.5 to the subjective wellbeing construct indicating acceptable validity (Hair et al. 1998). In addition, the path coefficient observed between subjective wellbeing and global life satisfaction constructs and both constructs are significantly correlated (r=0.812, p<0.001), which indicates good construct validity. Table 2 shows the convergent validity and construct reliability observed in the PWI Malay version. The average variance extracted (AVE) is 0.5781 suggesting adequate convergence validity (Hair et al. 1998). Three reliability coefficients observed are higher than 0.7 indicating excellent reliability (Nunnally et al. 1994).



**p<0.001

FIGURE 1. PWI Malay version domains loadings and inter-construct correlation

TABLE 2. Convergent validity and Construct reliability

Construct	AVE	Dijkstra-Henseler's rho (ρA)	Jöreskog's rho (ρc)	Cronbach's alpha (α)
Subjective Wellbeing	0.5781	0.8864	0.9046	0.8761
*AVE= Average variance extracted				

The comparison of PWI Malay version domains according to the sociodemographic characteristics is shown in Table 3. Among the sociodemographic characteristics and the PWI Malay version in the life domains, only personal health, achieving in life, and personal relationships showed a significant difference.

As for marital status sociodemographic characteristics, only the achieved in life and personal relationship domains showed significant differences. Satisfaction with achievement in life was significantly higher in married respondents (Median=7.00, IQR=5.00-8.25) compared to single respondents (Median=5.00, IQR=5.00), p=0.046, r=0.27. Satisfaction with personal relationships was also significantly higher among married respondents (Median=8.00, IQR=7.00-9.00) than among single respondents (Median=6.00, IQR=5.00-6.00), p=0.021, r=0.32. As for health issues, only the personal health domain showed significant differences. Satisfaction with their personal health was significantly higher in respondents with no health issues (Median=8.00, IQR=6.00-9.00) than in those with a health condition (Median=5.50, IQR=5.00-8.00), p=0.028, r=0.30.

TABLE 3. Comparison of Median, Interquartile range, significance value and effect size of marital status and health issues by PWI domains

PWI domains	Marital Status				Health Issues					
	Married	Not married			Yes		No			
Median IQR Median IQR			*p*	*r*	Median	IQR	Median	IQR	*p*	*r*
Personal Health					5.50	5.00-8.00	8.00	6.00-9.00	0.028	0.30

continue...

...cont.

Achieving in Life	7.00	5.00-8.25	5.00	5.00	0.046	0.27
Personal Relationship	8.00	7.00-9.00	6.00	5.00-6.00	0.021	0.32

*This table is to indicate that there are no other significant differences in the rest of variables in all PWI domains observed

DISCUSSION

Our findings reveal that the PWI Malay version has good convergent validity, construct validity, and construct reliability. After establishing the validity and reliability of the PWI Malay version, a comparison of wellbeing among caregivers based on sociodemographic characteristics was conducted. Out of the ten sociodemographic characteristics that have been analysed, only two showed a significant difference in satisfaction ratings on the three observed quality of life domains.

From a practical perspective, when items are usually derived from the definition of the construct of interest, it was meant to capture the construct intended at and only this construct (Ziegler et al. 2015). As a result, items on a scale are believed to seize differences in the same underlying construct. In this study, the PWI Malay version has eight domains that have good unidimensional properties to the subjective wellbeing construct. Convergent validity analyse the items as indicators of a specific construct that should converge or share a high proportion of variance in common (Hair et al. 1998). The AVE for the PWI Malay version showed adequate convergence meaning that the eight items, each that stands for a quality of life domain, adequately converge on the subjective wellbeing construct. In addition, three reliability coefficients observed in this study, representing the amount of random error in constructs scores, indicate that the PWI Malay version has good construct reliability.

The present study shows that caregivers caring for children with ASD with no health issues are more satisfied than caregivers with health issues. The health conditions reported by the caregivers of children with ASD in our study were high blood pressure and diabetes. It was in line with the results by Kamerawati et al. (2018) whereby respondents with high blood pressure mostly experienced a high level of parenting stress in 53.6% of fathers and 64.5% of mothers. A few studies have shown that an increase in parenting stress can lead to a decline in life quality (Hsiao et al. 2018; Johnson et al. 2011; Wang et al. 2020; Zeng et al. 2020). Moreover, caregiver health status was reported as one of the strongest predictors of quality of life among caregivers of adults with intellectual disabilities (Chou et al. 2007). Although this study by Chou et al. (2007) was conducted among caregivers of adults with intellectual disabilities, health status as the predictor of overall quality of life could carve a path towards studying personal health satisfaction of caregivers of children with ASD broadly in the future.

Moreover, satisfaction rating on achieving in life in quality of life domain is higher among caregivers of children with ASD who are married than those who are either divorced or widowed. A study by Benjak (2011) found that satisfaction with achieving in the life domain is statistically significant in predicting a higher subjective quality of life among parents of children with ASD and two other PWI quality of life domains. Besides that, Brewer et al. (2018) also reported that single mothers are seen to bear a greater burden of family care to ensure autistic children get the best possible treatment, which sometimes requires time and financial commitment. Adapting to the loss of income is more difficult for single and low-income mothers who have no choice than those who are married because they can rely on their spouse's income to support their family. Furthermore, spouses' immediate support can help decrease parental stress and boost family connection, increasing opportunities for all family members' needs to be satisfied and, as a result, improving parents' views of quality of life (Davis et al. 2009). In our study, married caregivers have higher satisfaction ratings towards achieving in life domain probably due to the fulfilled affection and support needs. Hence, together they embrace the hardship while caring for children with ASD, thus providing each a sense of achieving in life.

Besides that, married caregivers of children with ASD are also more satisfied with their relationships than caregivers who are either divorced or widowers. Personal relationships in this context could be referring to their partner or closest friends. In their study, Ilias et al. (2017) documented that the mothers have reported a lack of involvement from the fathers in caring for children with ASD and tired with house chores and caring for children with autism, which leads to arguments with their husbands. However, in our study, married caregivers caring for children with ASD are more satisfied with a personal relationship. One factor could be the equal commitment given by both parents. Hence, husband and wife are pleased

with their relationship when there are no arguments while caring for a child with ASD.

In our study, gender sociodemographic characteristics showed no significant difference in PWI quality of life satisfaction ratings. On the contrary, Nikmat et al. (2008) revealed that mothers experience a more substantial impact on their psychological wellbeing than fathers. Moreover, female caregivers of children with ASD reported more bodily pain, fatigue, tiredness (low vitality), and poorer mental health compared to men (Kheir et al. 2012). The present study shows no significant difference in satisfaction rating on PWI quality of life domains by caregivers of children with ASD based on the monthly income. However, a survey by Kamaralzaman et al. (2018) reported that most of the children with ASD that they studied receive free treatment from government health clinics and hospitals and a few of them also receive monetary aid. Hence, free medicines, lower treatment fees, and financial aids received by children with ASD probably have reduced the financial burden placed on their caregivers.

Moreover, race and the number of children with ASD showed no significant difference in satisfaction rating on PWI domains, which could be because the data was saturated into one category. Contrary to the findings by Nikmat et al. (2008), they reported a significant difference between occupation and psychological wellbeing of the parents of children with ASD while there is no significant difference in satisfaction rating on the domains observed based on the employment status in our study. Educational status also showed no significant difference in the satisfaction ratings in the present study domains. This could be due to the similarities between the three higher educational groups.

One of the limitations of this study is the sudden pandemic outbreak in Malaysia, which led to the national movement restriction order. This reduced the sample size targeted for the study. The absence of a normative index for the Malaysian population on the subjective wellbeing of caregivers of children with disabilities also limited the additional analysis regarding the overall wellbeing level of the caregivers of children with ASD.

CONCLUSION

PWI Malay version has good construct validity and reliability. Hence, it can be used to measure the subjective wellbeing among caregivers of children with ASD. Caregivers who are married are more satisfied with their achievements in life and personal relationships than single caregivers while caring for children with ASD. Caregivers of children with ASD who have health issues are less satisfied with their personal health than those with no health issues. The psychometric properties of the PWI Malay version can be further established in future studies. An effort to develop a national norm for the subjective wellbeing of Malaysians could also be made so that, wellbeing level can be interpreted.

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CONFLICTS OF INTEREST

The authors have no conflicts of interest to declare.

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Shobnaa A/P Tinagaran
Hanif Farhan Mohd Rasdi
Dzalani Harun
Kamaruddin Hassan
Shahirah Md Rasid
Occupational Therapy Programme,
Center for Rehabilitation & Special Needs,
Faculty of Health Science
Universiti Kebangsaan Malaysia
Jalan Raja Muda Abdul Aziz
50300 Kuala Lumpur, MALAYSIA

Correspondence: Hanif Farhan Mohd Rasdi

Email address: hanif_ot@ukm.edu.my