Sains Malaysiana 53(2)(2024): 433-446
http://doi.org/10.17576/jsm-2024-5302-16

QOL-DIS: A New Assessment in Analysing the Quality of Life of Persons with Disabilities

(QOL-DIS: Suatu Penilaian Baharu dalam Menganalisis Kualiti Hidup Orang Kurang Upaya)

Abd Aziz Alias[1], Nurul Hanis Aminuddin Jafry[2,*], Rohana Jani[3] & Mikkay Wong Ei Leen[4]

[1]*Department of Oral & Craniofacial Sciences, Faculty of Dentistry, Universiti Malaya, 50603 Kuala Lumpur, Malaysia*
[2]*School of Liberal Studies (CITRA), Universiti Kebangsaan Malaysia, 43600 UKM Bangi, Selangor, Malaysia*
[3]*Department of Decision Science, Universiti Malaya, 50603 Kuala Lumpur, Malaysia*
[4]*Department of Business Analytics, Sunway Business School, Sunway University, Bandar Sunway, 47500 Petaling Jaya, Selangor, Malaysia*

Received: 3 July 2023/Accepted: 15 January 2024

ABSTRACT

Accessing and monitoring the quality of life (QoL) of persons with disabilities (PWDs) is crucial in improving their QoL. Therefore, a reliable instrument is needed for that purpose. PWDs globally demand to get involved with anything related to their affairs, as stated in the movement slogan, "*Nothing about us, without us*". The WHOQOL-DIS is the instrument developed by WHO and is used widely to assess the QoL of PWDs. However, the computation method is based on the unweighted score. Hence, this study proposes an approach to assess QoL using an index based on a weighted score, which allows the PWDs to rate each item according to their expectation or level of importance. An index approach is based on the total of the cognitive and emotional reactions or experiences compared with the expectations. Robust tests, namely correlation analysis, and uncertainty and sensitivity analysis, were conducted to check the robustness of the index approach. The findings showed that an index approach is reliable in the WHOQOL-DIS instrument to assess the QoL of PWDs. Nevertheless, the QoL score between the index approach and the initial method only shows significant differences in the environment and discrimination domain. Besides, this study also suggests having a ten-point Likert scale instead of a five-point Likert scale when assessing the QoL of PWDs using an index approach.

Keywords: Disabilities; index; Malaysia; quality of life; WHOQOL-DIS

ABSTRAK

Akses dan pemantauan kualiti hidup (QoL) orang kurang upaya (OKU) adalah sangat penting dalam meningkatkan kualiti hidup mereka. Justeru, instrumen yang boleh dipercayai diperlukan untuk memenuhi tujuan tersebut. OKU di seluruh dunia menuntut untuk terlibat dengan apa sahaja perkara yang berkaitan dengan hal ehwal mereka, seperti yang dinyatakan dalam slogan pergerakan, "Tiada apa-apa tentang kita, tanpa kita". WHOQOL-DIS merupakan instrumen yang dibangunkan oleh WHO dan digunakan secara meluas untuk menilai kualiti hidup OKU. Walau bagaimanapun, kaedah pengiraan yang digunakan dalam instrumen ini adalah berdasarkan skor tidak berwajaran. Justeru, kajian ini mencadangkan pendekatan untuk menilai QoL menggunakan indeks berdasarkan skor wajaran yang membolehkan OKU menilai setiap item mengikut jangkaan atau tahap kepentingan mereka. Pendekatan indeks adalah berdasarkan jumlah kognitif dan reaksi emosi atau pengalaman berbanding dengan jangkaan. Ujian keteguhan iaitu analisis korelasi dan analisis ketidakpastian serta analisis sensitiviti telah dijalankan untuk menyemak keteguhan bagi pendekatan indeks. Hasil kajian menunjukkan bahawa pendekatan indeks dalam instrumen WHOQOL-DIS boleh dipercayai untuk menilai QoL OKU. Namun begitu, skor QoL bagi pendekatan indeks dan kaedah awal hanya menunjukkan perbezaan yang signifikan bagi domain persekitaran dan diskriminasi. Selain itu, kajian ini turut mencadangkan penggunaan skala Likert sepuluh mata dan bukannya skala Likert lima mata untuk menilai QoL OKU menggunakan pendekatan indeks.

Kata kunci: Indeks; kualiti hidup; kurang upaya; Malaysia; WHOQOL-DIS

Introduction

Over the past two decades, the quality of life (QoL) concept has been applied incessantly to persons with disabilities (PWDs) (Memisevic et al. 2017; Schalock 2004). However, it is difficult to envisage the exact relationship between disability and QoL and identify the scale that relates to disability that affects the QoL (Memisevic et al. 2017). Disability is commonly associated with physical limitations when in reality, mental health issues have also been classified as a type of disability (Leonardi et al. 2012). Irrespective of nation and country, PWDs are known to face various challenges ranging from education to employment. On top of that, they are continuously being crippled not only socially but also politically which eventually leads to poverty (WHO 2015). Concurrently, it is evident that the QoL of PWDs are different in comparison to normal individuals and this is likely due to the negative attitude, perception, and ambivalent behaviour demonstrated by the society towards PWDs (Albrecht & Devlieger 1999; Louvet 2007; Park, Faulkner & Schaller 2003). Previous studies reported that PWDs are the nation's most significant minority and tend to be marginalized in all aspects of life (Ang 2014; Islam 2015; Ledman & Brown 1993; Tiun, Lee & Khoo 2011) experiencing extreme hardship leading to poor QoL (Ledman & Brown 1993; Tiun, Lee & Khoo 2011).

In light of the crucialness of improving the QoL of PWDs, it is pertinent to identify reliable and appropriate ways to assess the existing level of QoL for PWDs. Therefore, assessing the QoL of PWDs leads to identifying socio-demographic groups with relatively low QoL and specific variables that should be prioritized to improve their level of QoL. However, no single definition is endorsed in determining the QoL and disability (Grabowska et al. 2021; Kimura & Silva 2009; Lazim & Osman 2009; Shakespeare 2006). Consequently, in drawing an analogy to the QoL, disability can be defined from various perspectives since it is a multidimensional concept that may include objective and subjective characteristics.

For a developing country like Malaysia, assessing the QoL of PWDs is urgently required to attain reliable information on the development of PWDs' well-being. The Malaysian government has persistently shown a high commitment to improve the QoL of PWDs in this country. These commitments are evident based on the participation in the Convention on the Rights of Persons with Disabilities (CRPD), implementation of the Incheon Strategy in Malaysia, enforcement of the Person with Disabilities Act 2008, implementation of the Plan of Action on Health Care for Persons with Disabilities 2011-2020 by the Ministry of Health Malaysia, as well as the policy formulation on PWDs under the 11th Malaysian Plan (Abdul Rahim et al. 2017; Ahmad et al. 2017; Tah & Mokhtar 2016). However, incomprehensive information will be difficult for the government to determine the effectiveness of the implemented policies and programs that are aimed at improving the QoL of PWDs.

Like other developing countries, Malaysia too is moving away from a charity-based approach to a right-based approach in managing PWDs affairs (Tah 2014; Tah & Mokhtar 2016). There is a substantial demand from the PWDs community to involve them in designing or developing programs and policies for PWDs. "Nothing about us, without us" - a motto from the disability rights movement that addresses PWD issues - reflects the significance of this demand for the PWD community (Derby 2013; Franits 2005; Scotch 2009). In response to that demand, this study proposed an index approach to assessing the QoL of PWDs. An index approach introduces weighted scores in computing the QoL score. The weighted scoring will allow the PWDs to rate their expectations or determine the importance of each facet or item in the WHOQOL-DIS instrument.

WHOQOL-DIS is a generic instrument developed specifically to measure the QoL of PWDs which is suitable to be used cross-culturally. This instrument combines an existing WHOQOL-BREF and WHOQOL-100 with the addition of a new supplemental module (disability module) (Power & Green 2010). This generic instrument has proven as a reliable instrument to measure the QoL of PWDs (Bredemeier et al. 2014; Lee, Jang & Choi 2017; Lucas-Carrasco et al. 2011).

In reality, some life aspects may be more critical than others to an individual's QoL, thus the corresponding items should contribute more to the total score of QoL (McGrath & Bedi 2004; Wu & Yao 2006). According to Hsieh (2004), the possibility that not all aspect of life is equally important to all individuals has been recognized by many researchers. The same situation is observed in PWDs; for example, a physically impaired person may have a different need that is more important than the visually impaired person. Therefore, this study constructed an index approach to assess the QoL of PWDs known as the QoL-DIS index. The main advantage of this approach is that it allows the PWDs to rate their expectations or determine how important each facet or item in the WHOQOL-DIS instrument is to them.

Methods

QoL index was calculated based on the total cognitive and emotional reactions or experience with a comparison drawn against their expectations, needs, and aspirations (Dijkers 2003). The construction of the index in this study is based on the guideline issued by the Organization for Economic Co-operation and Development (OECD) and previous studies (Foa & Tanner 2012; Greyling

& Tregenna 2017; Groh & Wich 2009; OECD 2008; Talukder, Hipel & vanLoon 2017; Wiebe et al. 2003). Generally, there are five stages in constructing the QoL index (Foa & Tanner 2012; Greyling & Tregenna, 2017; Groh & Wich 2009; OECD 2008; Talukder, Hipel & vanLoon 2017; Wiebe et al. 2003) as an alternative measurement to assess the QoL of PWDs using the WHOQOL-DIS instrument. The stages include the selection of indicators, normalizing the data, choosing the appropriate weighting technique, aggregation schemes for constructing the index, and checking the robustness of the newly constructed index as depicted in Figure 1.

During index construction, the relationship between the items was considered with the objective of combining the items into a single and one-dimensional domain. Each item was assigned into two types of responses, which are the level of importance or expectation (B) and the level of experience (C) they faced. The response for the level of importance uses a five-point scale, that is 1= Not important, 2 = A little important, 3 = moderately important, 4 = very important, and 5 = extremely important. In addition, the level of experience consists of four types of response scale (Table 1), which were applied depending on the statement of the items.

Assessing the QoL of PWDs using an index also allows the researcher to have an insight into the differences of certain items based on types of disabilities. For example, expectations regarding 'mobility' differ between physically disabled people and people with hearing and speech impairments, as they have had different experiences with mobility. The situation is similar for the items 'body image and appearance'. A visually impaired person has different expectations than a physically disabled person or a hearing or speech impaired person.

SELECTION OF THE INDICATORS

The selection of the indicators was guided by a top-down approach, whereby the items and domains used to assess the QoL of PWDs were adopted from the WHOQOL-DISinstrument. This instrument is reliable in measuring the QoL of PWDs (Bredemeier et al. 2014; Lucas-Carrasco et al. 2010; Power & Green 2010). Overall, there are 36 items across seven domains with three global items from the WHOQOL-DIS being used in this study. In this study, the index was developed based on multiple facets/items from the domains in the WHOQOL-DIS instruments. The items were summated or combined to derive a single measurement or scale for each WHOQOL-DIS domain. Items in the social relationship domain namely the 'sexual activity' was removed since this item is usually unanswered leading to a high missing value. As a result, 35 items across seven domains as well as 3 global items were used in the calculation. The diagrammatic representation of the domains and its facets are as tabulated in Table 2.

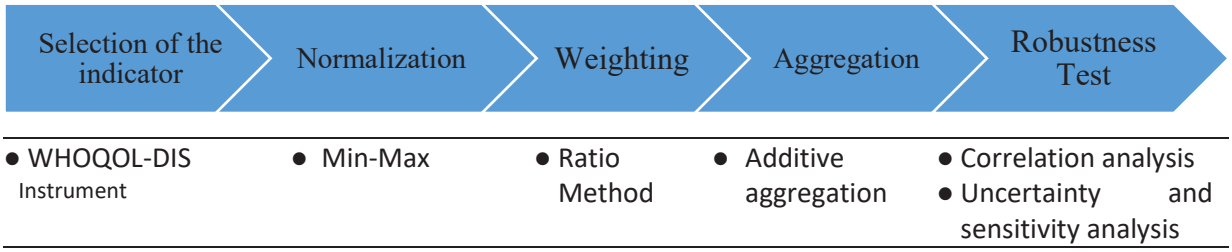

FIGURE 1. Steps and method of constructing the QoL-DIS Index

TABLE 1. The level of experience

Types of response	Scale				
	1	2	3	4	5
Intensity	Not at All	A Little	A moderate amount	Very much	An extreme amount
Evaluation	Very poor	Poor	Neither poor nor good	Good	Very good
Satisfaction	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
Capacity	Not at all	A little	Moderately	Mostly	Completely
Frequency	Never	Seldom	Quite often	Very often	Always

TABLE 2. Domains and facets of the WHOQOL-DIS Instrument

	Notation	Facet
Global items General QoL General health Impact of disability		
Domains		
Physical health	B_3, C_3	pain and discomfort
	B_4, C_4	dependence on medicinal substances and medical aids
	B_{10}, C_{10}	energy and fatigue
	B_{15}, C_{15}	mobility
	B_{16}, C_{16}	sleep and rest
	B_{17}, C_{17}	activities of daily living
	B_{18}, C_{18}	work capacity
Psychological	B_5, C_5	bodily image and appearance
	B_6, C_6	negative feelings
	B_7, C_7	positive feelings
	B_{11}, C_{11}	self-esteem
	B_{19}, C_{19}	spirituality/religion/personal beliefs
	B_{26}, C_{26}	thinking, learning, memory and concentration
Social relationships	B_{20}, C_{20}	personal relationships
	B_{22}, C_{22}	social support
Environment	B_8, C_8	financial resources
	B_9, *C9*	freedom, physical safety and security
	B_{12}, C_{12}	health and social care: accessibility and quality
	B_{13}, C_1	home environment
	B_{14}, C_{14}	opportunities for acquiring new information and skills
	B_{23}, C_{23}	participation in and opportunities for recreation/leisure activities
	B_{24}, C_{24}	physical environment (pollution/ noise/traffic/climate)
	B_{25}, C_{25}	transport
Discrimination	B_{28}, C_{28}	discrimination
	B_{29}, C_{29}	advocacy
	B_{30}, C_{30}	future prospects
Autonomy	B_{31}, C_{31}	control
	B_{32}, C_{32}	choice
	B_{33}, C_{33}	autonomy
Inclusion	B_{34}, C_{34}	communication ability
	B_{35}, C_{35}	social acceptance
	B_{36}, C_{36}	respect
	B_{37}, C_{37}	social network and interaction
	B_{38}, C_{38}	social inclusion and contribution
	B_{39}, C_{39}	personal potential

DATA USED

This study consisted of 340 PWDs as the respondents (Table 3). The respondents were stratified according to three categories of disabilities namely physically disabled, visually impaired, as well as hearing and speech impaired. Written informed consents were obtained from the participants before conducting the survey. About 26.8 percent of the 340 respondents were hearing and speech impaired, 14.7 percent were visually impaired, and 58.5 percent were physically disabled. Male respondents constituted around 69.1 percent of the respondents while 30.9 percent were female, which equates roughly to the gender distribution of PWDs in the population. The mean age of the respondents was 32.06 years old (SD = 12.99). The result showed that 64.0 percent of the respondents felt that their health is in good condition while 36.0 percent reported otherwise. Around 56.7 percent of the PWDs were not disabled at birth.

NORMALIZATION

In order to realize the aggregation index, all data points need to be normalized. Several transformations and/or normalization techniques are available and applicable such as the Z-score (Standardisation), the Min-max technique, and proportionate normalization (Groh & Wich 2009; OECD 2008; Talukder, Hipel & vanLoon 2017). This study employed the min-max technique to normalize the data. This is a common technique and has been employed in the construction of composite indicators (Talukder, Hipel & vanLoon 2017). The advantage of using this method is that the boundaries can be arranged, and all indicators are identical in terms of the range (0, 1) (Talukder, Hipel & vanLoon 2017). The normalization formula is as follow:

$$\chi_i = \frac{C_i - min(C_i)}{(C_i) - min(C_i)} \quad (1)$$

where C_i is a variable C for indicator; i, $min(C_i)$ refer to smallest observed value; and $max(C_i)$ are the largest observed value.

TABLE 3. Demographics characteristic

	Frequency	Percent %
Types of Disabilities		
Hearing & Speech Impaired	91	26.8
Visually Impaired	50	14.7
Physically Disabled	199	58.5
Age Group (Years)		
18 – 24	136	40.0
25 – 39	102	30.0
40 – 59	88	25.9
60 and above	14	4.1
Gender:		
Male	235	69.1
Female	105	30.9
Self-evaluate Health Condition		
Healthy	217	64.0
Unhealthy	122	36.0
Became disabled person		
Since birth	104	43.3
Not disabled since birth	136	56.7

Weighting

The weight of each item was calculated using a ratio method based on the level of importance rated by the respondent. Commonly, the weightage is determined by three methods namely the equal weight, statistical model, and expert opinion. The Ratio Method, which was employed in this study is based on a statistical model calculating the weight according to the level of importance. The weight formula is shown below:

$$W_i = \frac{Important\ score\ of\ Item\ (B_i)}{Total\ Important\ score} \times 100\ ,\ 0 \leq W_i \leq 1 \quad (2)$$

Index computation

There are two methods of aggregation that are normally used to compute the composite index namely the additive aggregation and the geometric aggregation method. This study employed the additive aggregation method as detailed below:

$$DI = \sum_{i=1}^{n} X_i W_i \quad (3)$$

where *DI* is subdomain index; *n* is the number of item; χ_i refer to level of experience (normalized); and W_i is weight.

ROBUSTNESS CHECK

During the processes of constructing the QoL-DIS index, several subjective judgments have been made such as the selection of the normalization method, weighting scheme, and the aggregation technique. Therefore, it is necessary to examine the robustness of the final constructed QoL-DIS index. In general, there are various statistical tests that can be used to determine the reliability of the QoL-DIS index including Cronbach's alpha, test-retest reliability using the intraclass correlation coefficient (ICC), correlation analysis, and uncertainty and sensitivity analysis. Nonetheless, this study applied two methods, specifically, the correlation analysis and the uncertainty and sensitivity analysis.

Firstly, correlation analysis was used to test the robustness of the QoL-DIS index. The correlation coefficient will determine if the result of the QoL-DIS index is heavily influenced by the choice of normalization, weightage, and aggregation methods (Talukder, Hipel & vanLoon 2017). The second method employed is uncertainty and sensitivity analysis. The uncertainty and sensitivity analysis help to gauge the robustness of the composite indicator and to improve the transparency (OECD 2008). Uncertainty analysis refers to the process of assessing how uncertainties in input factors propagate through the structure of the composite indicator and affect the composite indicator values. Meanwhile, sensitivity analysis is used to assess the contribution of the individual source of uncertainty towards the variance output.

RESULT

Table 4 demonstrates the index values after the construction process, spanning from the second to the fourth stages. This process involves the normalization of data (X_i), followed by the computation of the weight (W_i), and lastly, the computation of the index.

ROBUSTNESS ASSESSMENT OF THE INDEX METHOD

The final stage of constructing an index is to check its robustness. The index approach that was constructed in this study is known as QoL-DIS index. The robustness of the constructed QoL-DIS index is tested by utilizing two methods, specifically, correlation analysis as well as uncertainty and sensitivity analysis. The first was to form a correlation between the four different combinations of normalization and weightage methods. The second method was to use uncertainty and sensitivity analysis to assess the contribution of the individual source of uncertainty towards the output variance.

CORRELATION ANALYSIS

The combination of different normalization techniques and different weightage methods were correlated to assess the impact of every different combination. Two different techniques of normalization namely the Z-score normalization and Min-Max Normalization, as well as two different methods of weightage (ratio method and equal weightage), were used producing four different results. All of the normalization techniques and weightage methods influenced the outcome of the index values, therefore, it is important to compare all different combinations of normalization and weighting methods. Herewith are the combinations of normalization techniques and weightage methods: 1). ZscoreRM = Z-Score Normalization and Ratio Method Weightage, 2) ZscoreEM = Z-Score Normalization and Equal Weightage, 3) MinMaxRM = Min-Max Normalization and Ratio Method Weightage, and 4) MinMaxEM = Min-Max Normalization and Equal Weightage.

TABLE 4. QoL-DIS Index

	Formula
Physical health Index (PhI)	$\sum (\chi_i w_i) \times 100$ $= (\chi_3 w_3 + \chi_4 w_4 + \chi_{10} w_{10} + \chi_{15} w_{15} + \chi_{16} w_{16} + \chi_{17} w_{17} + \chi_{18} w_{18}) \times 100$ $0 \leq PhI \leq 100$
Psychological Index (PhyI)	$\left(\sum \chi_i w_i\right) \times 100$ $= (\chi_5 w_5 + \chi_6 w_6 + \chi_7 w_7 + \chi_{11} w_{11} + \chi_{19} w_{19} + \chi_{26} w_{26}) \times 100$ $0 \leq PhyI \leq 100$
Social relationship Index (SrI)	$(\sum \chi_i w_i) \times 100$ $= (\chi_{20} w_{20} + \chi_{22} w_{22}) \times 100$ $0 \leq PhyI \leq 100$
Environment Index (EnvI)	$(\sum \chi_i w_i) \times 100$ $= (\chi_8 w_8 + \chi_9 w_9 + \chi_{12} w_{12} + \chi_{13} w_{13} + \chi_{14} w_{14} + \chi_{23} w_{23} + \chi_{24} w_{24} + \chi_{25} w_{25}) \times 100$ $0 \leq EnvI \leq 100$
Discrimination Index (DisI)	$(\sum \chi_i w_i) \times 100$ $= (\chi_{28} w_{28} + \chi_{29} w_{29} + \chi_{30} w_{30}) \times 100$ $0 \leq DisI \leq 100$
Autonomy Index (AutI)	$(\sum \chi_i w_i) \times 100$ $= (\chi_{31} w_{31} + \chi_{32} w_{32} + \chi_{33} w_{33}) \times 100$ $0 \leq AutI \leq 100$
Inclusion Index (IncI)	$(\sum \chi_i w_i) \times 100$ $= (\chi_{34} w_{34} + \chi_{35} w_{35} + \chi_{36} w_{36} + \chi_{37} w_{37} + \chi_{38} w_{38} + \chi_{39} w_{39}) \times 100$ $0 \leq IncI \leq 100$

The results of the robustness tests using correlation analysis of the different combination of normalization and weightage methods among seven QoL domains are presented in the appendices (Table A1-Tables A7). The results of the correlation analysis showed that the normalization technique and weightage method do not cause a significant influence on the result of the index. All four different combinations of normalization techniques and weightage methods showed a very high correlation in all seven domains. Based on these findings, it was concluded that the newly constructed QoL-DIS was robust.

UNCERTAINTY AND SENSITIVITY ANALYSIS

Since the process of constructing seven domains of the QoL-DIS index depends on the choice of normalization method, weightage, and aggregation technique, therefore, the constructed index would reflect the unavoidable elements of uncertainty. The normalization techniques and weightages were calculated using several different methods, hence the values of the final index are different with each calculation. The uncertainty and sensitivity analysis in this study aims to assess the effects of uncertainty elements (separately or jointly) towards the

performance of the seven domains of the QoL-DIS index. To analyze the sensitivity of the normalization techniques and weightage methods when constructing the new QoL index, a comparison was made between the values of all domains of the QoL-DIS index with the values of the WHOQOL-DIS domains (Table 5).

The result of the sensitivity analysis of the seven domains of QoL-DIS index for normalization and weighting technique showed the insensitivity of all domains (except the environment domain) towards these elements. Although the difference in value between QoL-DIS and WHOQOL-DIS for the environment domain is sensitive (p-value < 0.05), the difference is too small (0.39%). Apart from the robustness test, uncertainty and sensitivity analysis were also used to interpret the results. The construction of the QoL-DIS index provides rankings for the combination of two normalization methods and two weighting techniques that meet the methodological assumptions. The four scenarios were tested explicitly as depicted in Table 6. Therefore, conducting additional uncertainty and sensitivity analysis would be redundant. Nevertheless, the robustness was assessed and the results are shown in Figure 2. The higher the number of occurring overlaps, the more robust are the rankings (Talukder, Hipel & vanLoon 2017). A correlation analysis was performed together with the uncertainty and sensitivity analysis on the index in order to provide conclusive evidence on the robustness of the QoL-DIS Index.

TABLE 5. Comparison mean score between WHOQOL-DIS WITH QoL-DIS Index

		WHOQOL-DIS		QoL- DIS Index		Differences	p-value
Domain		Mean	SD	Mean	SD	Mean	SD
Physical health	64.33	14.43	64.54	15.06	-0.21	3.87	0.311
Psychological	67.93	14.56	68.11	14.77	-0.18	1.88	0.077
Social relationship	71.41	17.81	71.67	19.19	-0.26	12.02	0.691
Environment	66.59	15.50	66.97	15.43	-0.39	1.48	0.000
Discrimination	45.72	21.45	45.36	21.75	0.35	3.21	0.044
Autonomy	67.45	20.23	67.58	20.41	-0.12	1.37	0.098
Inclusion	63.97	19.13	64.21	19.11	-0.25	3.38	0.176

TABLE 6. Rankings by different weighting and normalization methods

	Z-Score Normalization				Min-Max Normalization			
	EW	Rank	RM	Rank	EW	Rank	RM	Rank
Domain								
Physical health	71.29	6	71.66	6	64.18	5	64.44	5
Psychological	74.31	2	74.41	2	67.92	2	68.03	2
Social relationship	77.10	1	77.20	1	71.46	1	71.58	1
Environment	73.21	4	73.42	4	66.58	4	66.83	4
Discrimination	56.53	7	56.36	7	45.66	7	45.31	7
Autonomy	73.86	3	73.99	3	67.40	3	67.59	3
Inclusion	71.89	5	72.30	5	63.68	6	64.12	6

EW = Equal Weighting; RM = Ratio Method

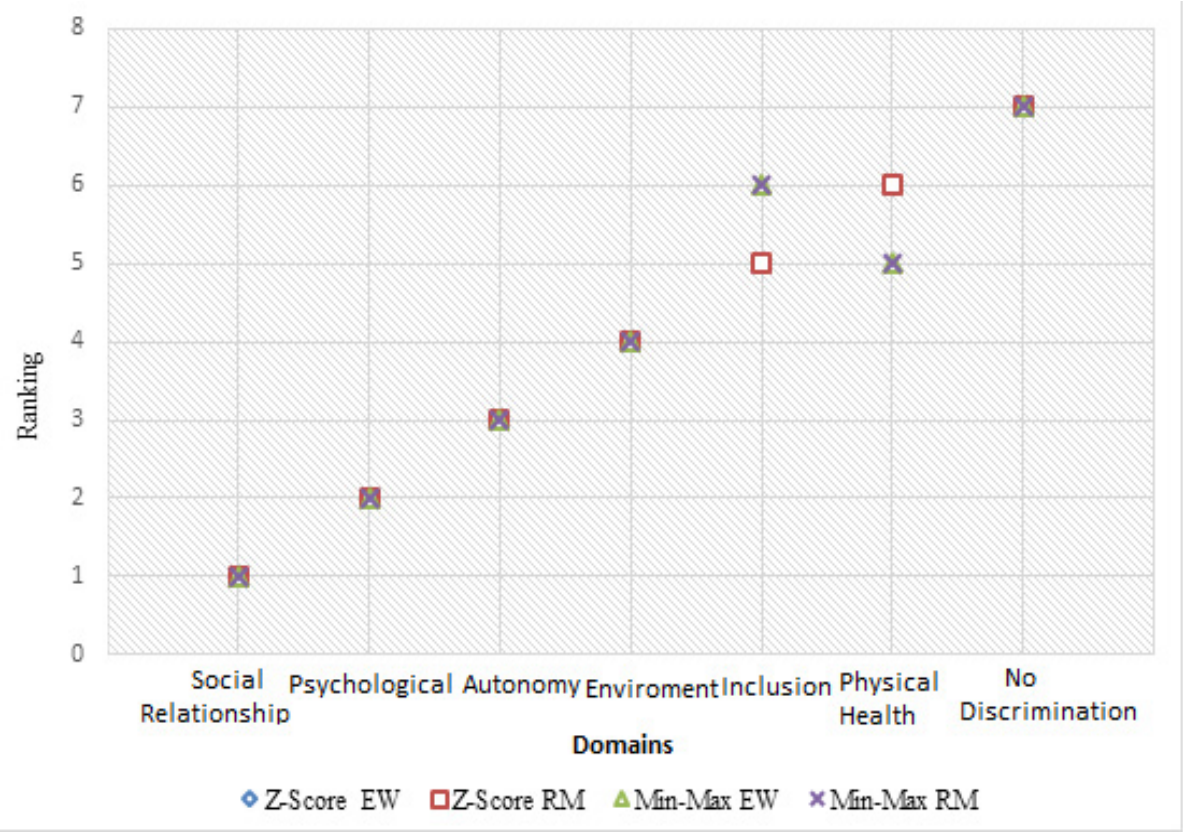

FIGURE 2. Ranking by different method

DISCUSSIONS AND CONCLUSION

Based on the findings of this study, it can be noted that the quality of life of PWDs are better accessed using the index constructed based on the WHOQOL-DIS instrument. Results using the index approach, known as QoL-DIS in this study, showed that the social relationship domain has the highest score, while the discrimination domain scored the lowest, which is similar to the score results calculated using WHOQOL-DIS. The other domains also showed a similar ranking of scores. The results showed that assessing quality of life using QoL-DIS Index produces similar results to the WHOQOL-DIS method. The scores obtained for all the QoL domains based on this index showed no significant difference between both methods except for the environment and discrimination domain but with a very small difference (0.39 and 0.35%). However, the QoL-DIS index has an advantage over the WHOQOL-DIS approach because of the weightage set in the computation, taking into account the importance of the items rated by the respective PWDs. Hence, it represents a more personal anticipation of PWDs on the element(s) that need (s) improvement in the enhancement of their QoL.

Although the WHOQOL-DIS has been proven as a reliable instrument to measure QoL of PWDs and used widely (Bredemeier et al. 2014; Lee, Jang & Choi 2017; Lucas-Carrasco et al. 2010), the QoL-DIS index developed in this study introduced a way of assessing the quality of life for PWDs that is able to recognise the different expectation of PWDs on the QoL items by incorporating weightage in the measurement. Irrefutably, there are studies which reported that weighting score based on the level of importance is unnecessary as its rating does not have any beneficial effect in predicting the overall satisfaction with life (Wu & Yao 2006). Nonetheless, it is imperative to acknowledge that individual's preference including PWDs is different and cannot be elicited directly (Hsieh 2004; Poppitz 2017). Therefore, the collection of preferences and the transformation into weights must rely on the statistical methods that are able to recognise the differences

(Poppitz 2017). The index approach applied in this study provides the opportunity for the PWDs to self-rate their expectation on the importance of each item in assessing their QoL. This opportunity is in line with the slogan from the disability right movement, "*Nothing about us, without us"*, PWDs should be at the forefront of any decision or policy-making that affects their lives (Derby 2013; Franits 2005; Scotch 2009). In addition, an index approach is in line with the self-determination philosophy, "*seek to maximize autonomy and choice and ensure that persons with disabilities are empowered to live as independently as possible*" (Kietzman & Benjamin 2016). The self-determination philosophy includes not only PWDs are deciding what is important to them and what they want but also are being in charge of their daily decisions (Friedman & VanPuymbrouck 2019).

In this study, the index is calculated based on a five-point Likert scale which lacks in sensitivity to be able to capture the variation between expectation and experience of PWDs towards WHOQOL-DIS domains. It is therefore recommended for future research to use a ten-point Likert scale when assessing quality of life using the proposed index approach. The utilization of a ten-point Likert scale enhances the sensitivity to discrepancies between expected levels and actual experiences. As a result, the index calculation becomes more refined and able to capture the variations in discrepancies, thereby enhancing the accuracy and insightfulness of the assessment of QoL. With reference to past instruments, for instance Ferrans and Power Quality of Life Index and the Wisconsin Quality of Life Index, it can be concluded that application of index approach in assessing QoL is indeed reliable.

It is pertinent to identify and understand the importance of specific elements or domains when assessing the QoL of PWDs in Malaysia. This understanding is essential for obtaining reliable information and gaining valuable insights, thereby facilitating the development of targeted programs and activities aimed at enhancing their well-being. With this information, the government and other relevant bodies would be able to measure the impact and determine whether the policies and programs have been implemented successfully in improving the well-being of PWDs. Irrefutably, there are various methods which have been developed to assess QoL using the index approach for example, Ferrans and Powers Quality of Life Index (Ferrans & Powers 1992), the Wisconsin Quality of Life Index (Diamond & Becker 1999) and the New Malaysian Quality of Life Index based on Fuzzy Sets and Hierarchical Needs (Lazim & Osman 2009). Nevertheless, these methods were designed with a specific objective which targets a specific group which does not include the PWDs. Therefore, this study proposes an index known as QoL-DIS Index to assess quality of life specifically for PWDs in Malaysia that is able to recognise the expectation of PWDs on the elements or items that reflects their level of QoL. The advantages of assessing the quality of life using an index approach are firstly; it allows PWDs to rate the degree of importance of each item in all the QoL domains measured according to their perspective. Secondly, the method of calculating QoL-DIS Index is more exhaustive, in which different weightage is assigned to each item based on the feedback reported by the PWDs themselves.

In summary, while the index approach allows people with disabilities to rate the level of expectations in relation to each facet of the WHOQO-DIS tool, this study shows that there is no significant difference from the original method. Therefore, the QoL-DIS index is an alternative method for assessing the quality of life of people with disabilities, but the existing method of the WHOQOL-DIS instrument is suitable for accessing the quality of life of people with disabilities.

REFERENCES

Abdul Rahim, A., Samad, A., Amirah, N., Said, I., Seman, W. & Amin, W. 2017. Malaysian plan of action for people with disabilities 2016-2022: Way forward. *UIA 2017 Seoul World Architects Congress.* Seoul, South Korea. 3rd-10th September 2017.

Ahmad, N.A., Kasim, N.M., Mahmud, N.A., Yusof, Y.M., Othman, S., Chan, Y.Y. & Aziz, F.A.A. 2017. Prevalence and determinants of disability among adults in Malaysia: Results from the National Health and Morbidity Survey (NHMS) 2015. *BMC Public Health* 17(1): 756-766.

Albrecht, G.L. & Devlieger, P.J. 1999. The disability paradox: High quality of life against all odds. *Social Science & Medicine* 48(8): 977-988.

Ang, M.C. 2014. Do Persons with Disabilities Act (2008) and organizational culture influence managerial intention to hire persons with disabilities?: The Malaysian perspective. *Jurnal Pengurusan* 41: 81-90.

Bredemeier, J., Wagner, G.P., Agranonik, M., Perez, T.S. & Fleck, M.P. 2014. The World Health Organization Quality of Life instrument for people with intellectual and physical disabilities (WHOQOL-Dis): Evidence of validity of the Brazilian version. *BMC Public Health* 14(1): 1-12.

Derby, J. 2013. Nothing about us without us: Art education's disservice to disabled people. *Studies in Art Education* 54(4): 376-380.

Diamond, R. & Becker, R. 1999. Wisconsin Quality of Life Index (W-QLI): A multidimensional model for measuring quality of life. *Journal of Clinical Psychiatry* 60(3): 29-31.

Dijkers, M.P. 2003. Individualization in quality of life measurement: Instruments and approaches. *Archives of Physical Medicine and Rehabilitation* 84(Supplement 2): S3-S14.

Ferrans, C.E. & Powers, M.J. 1992. Psychometric assessment of the Quality of Life Index. *Research in Nursing & Health* 15(1): 29-38.

Foa, R. & Tanner, J.C. 2012. *Methodology of the Indices of Social Development*. ISD Working Paper Series 2012-04, International Institute of Social Studies of Erasmus University Rotterdam (ISS), The Hague.

Franits, L.E. 2005. Nothing about us without us: Searching for the narrative of disability. *Am. J. Occup. Ther.* 59(5): 577-579.

Friedman, C. & VanPuymbrouck, L. 2019. The impact of people with disabilities choosing their services on quality of life outcomes. *Disability and Health Journal* 12(2): 187-194.

Grabowska, I., Antczak, R., Zwierzchowski, J. & Panek, T. 2021. Individual quality of life and the environment - towards a concept of liveable areas for persons with disabilities in Poland. *BMC Public Health* 21: 740.

Greyling, T. & Tregenna, F. 2017. Construction and analysis of a composite quality of life index for a region of South Africa. *Social Indicators Research* 131(3): 887-930.

Groh, A.P. & Wich, M. 2009. A composite measure to determine a host country's attractiveness for foreign direct investment. *IESE Business School Working Paper No. 833.* https://dx.doi.org/10.2139/ssrn.1550717

Hsieh, C.M. 2004. To weight or not to weight: The role of domain importance in quality of life measurement. *Social Indicators Research* 68(2): 163-174.

Islam, M.R. 2015. Rights of the people with disabilities and social exclusion in Malaysia. *International Journal of Social Science and Humanity* 5(2): 171-177.

Kietzman, K.G. & Benjamin, A. 2016. Who's in charge? A review of participant direction in long-term care. *Public Policy & Aging Report* 26(4): 118-122.

Kimura, M. & da Silva, J.V. 2009. Ferrans and powers Quality of Life index. *Revista da Escola de Enfermagem da USP* 43(SPE): 1098-1104.

Lazim, M.A. & Osman, M.T.A. 2009. A new Malaysian Quality of Life index based on fuzzy sets and hierarchical needs. *Social Indicators Research* 94(3): 499-508.

Ledman, R. & Brown, D. 1993. The Americans with disabilities act: The cutting edge of managing diversity. *SAM Advanced Management Journal* 58(2): 17-20.

Lee, K.J., Jang, H.I. & Choi, H. 2017. Korean translation and validation of the WHOQOL-DIS for people with spinal cord injury and stroke. *Disability and Health Journal* 10(4): 627-631.

Leonardi, M., Raggi, A., Pagani, M., Carella, F., Soliveri, P., Albanese, A. & Romito, L. 2012. Relationships between disability, quality of life, and prevalence of nonmotor symptoms in Parkinson's disease. *Parkinsonism & Related Disorders* 18(1): 35-39.

Louvet, E.J.R.P. 2007. Social judgment toward job applicants with disabilities: Perception of personal qualities and competences. *Rehabilitation Psyhology* 52(3): 297-303.

Lucas-Carrasco, R., Pascual-Sedano, B., Galán, I., Kulisevsky, J., Sastre-Garriga, J. & Gomez-Benito, J. 2010. Using the WHOQOL-DIS to measure quality of life in persons with physical disabilities caused by neurodegenerative disorders. *Neurodegenerative Diseases* 8(4): 178-186.

McGrath, C. & Bedi, R. 2004. Why are we 'weighting'? An assessment of a self-weighting approach to measuring oral health-related quality of life. *Community Dent. Oral. Epidemiol.* 32(1): 19-24.

Memisevic, H., Hadzic, S., Ibralic Biscevic, I. & Mujkanovic, E. 2017. Quality of life of people with disabilities in Bosnia and Herzegovina - is there a moderating effect of the health status? *Scandinavian Journal of Disability Research* 19(4): 375-382.

OECD/European Union/EC-JRC. 2008. *Handbook on Constructing Composite Indicators: Methodology and User Guide*. Paris: OECD Publishing. https://doi.org/10.1787/9789264043466-en

Park, J.H., Faulkner, J. & Schaller, M. 2003. Evolved disease avoidance processes and contemporary anti-social behavior: Prejudicial attitudes and avoidance of people with physical disabilities. *Journal of Nonverbal Behavior* 27(2): 65-87.

Poppitz, P. 2017. Can subjective data improve inequality measurement? A multidimensional index of economic inequality. *ECINEQ Working Paper 2017-446.* http://www.ecineq.org/2017/09/01/can-subjective-data-improve-inequality-measurement-a-multidimensional-index-of-economic-inequality/

Power, M.J. & Green, A.M. 2010. Development of the WHOQOL disabilities module. *Quality of Life Research* 19(4): 571-584.

Schalock, R.L. 2004. The emerging disability paradigm and its implications for policy and practice. *Journal of Disability Policy Studies* 14(4): 204-215.

Scotch, R.K. 2009. Nothing about us without us: Disability rights in America. *OAH Magazine of History* 23(3): 17-22.

Shakespeare, T. 2006. The social model of disability. *The Disability Studies Reader* 2: 197-204.

Tah, I.H.M. 2014. Orang Kurang Upaya (OKU) dan hak untuk hidup: Satu analisis perundangan di Malaysia. *International Conference on Law, Policy and Social Justice (ICLAPS 2014)*. Penang, Malaysia. 10-11 September.

Tah, I.H.M. & Mokhtar, K.A. 2016. Malaysia's ratification of the UN Convention on the Rights of Persons with Disabilities (UN CRPD). *International Journal of Business, Economics and Law* 11(4): 83-87.

Talukder, B., Hipel, K.W. & vanLoon, G.W. 2017. Developing composite indicators for agricultural sustainability assessment: Effect of normalization and aggregation techniques. *Resources* 6(4): 66.

Tiun, L., Lee, L. & Khoo, S. 2011. Employability of people with disabilities in the northern state of Peninsular Malaysia: Employers' perspective. *Disability, CBR and Inclusive Development Journal* 22(1): 79-94.

World Health Organization (WHO). 2015. *WHO Global Disability Action Plan 2014-2021: Better Health for All People with Disability*. Geneva: World Health Organization.

Wiebe, S., Guyatt, G., Weaver, B., Matijevic, S. & Sidwell, C. 2003. Comparative responsiveness of generic and specific quality-of-life instruments. *Journal of Clinical Epidemiology* 56(1): 52-60.

Wu, C-H. & Yao, G. 2006. Do we need to weight satisfaction scores with importance ratings in measuring quality of life? *Social Indicators Research* 78(2): 305-326.

*Corresponding author; email: hanisaj@ukm.edu.my

TABLE A1. Spearman correlation (%) of Physical Health Index

	ZscoreRM	ZscoreEW	MinMaxRM	MinMaxEW
ZscoreRM	100.0			
ZscoreEW	98.7	100.0		
MinMaxRM	100.0	98.4	100.0	
MinMaxEW	98.6	99.7	98.4	100.0

TABLE A2. Spearman correlation (%) of Psychological Index

	ZscoreRM	ZscoreEW	MinMaxRM	MinMaxEW
ZscoreRM	100.0			
ZscoreEW	100.0	100.0		
MinMaxRM	98.7	98.7	100.0	
MinMaxEW	99.3	99.3	99.0	100.0

TABLE A3. Spearman correlation (%) of Social relationship Index

	ZscoreRM	ZscoreEW	MinMaxRM	MinMaxEW
ZscoreRM	100.0			
ZscoreEW	98.0	100.0		
MinMaxRM	98.1	98.9	100.0	
MinMaxEW	97.5	99.1	99.4	100.0

TABLE A4. Spearman correlation (%) of Environment Index

	ZscoreRM	ZscoreEW	MinMaxRM	MinMaxEW
ZscoreRM	100.0			
ZscoreEW	99.2	100.0		
MinMaxRM	100.0	99.2	100.0	
MinMaxEW	99.4	99.8	99.4	100.0

TABLE A5. Spearman correlation (%) of Discrimination Index

	ZscoreRM	ZscoreEW	MinMaxRM	MinMaxEW
ZscoreRM	100.0			
ZscoreEW	99.0	100.0		
MinMaxRM	99.8	98.4	100.0	
MinMaxEW	98.9	99.3	98.8	100.0

TABLE A6. Spearman correlation (%) of Autonomy Index

	ZscoreRM	ZscoreEW	MinMaxRM	MinMaxEW
ZscoreRM	100.0			
ZscoreEW	98.4	100.0		
MinMaxRM	99.3	98.6	100.0	
MinMaxEW	98.8	99.3	99.5	100.0

TABLE A7. Spearman correlation (%) of Inclusion Index

	ZscoreRM	ZscoreEW	MinMaxRM	MinMaxEW
ZscoreRM	100.0			
ZscoreEW	99.2	100.0		
MinMaxRM	99.9	99.3	100.0	
MinMaxEW	99.4	99.7	99.5	100.0