

Screening for health-related quality of life in children and adolescents with an autism spectrum disorder in Saudi Arabia



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ARTICLE INFO

Article history:

Received 7 January 2022

Received in revised form

12 April 2022

Accepted 13 April 2022

Keywords:

KIDSCREEN-52

Quality of life

Autism spectrum disorders

Saudi Arabia

ABSTRACT

Whilst there has been a growing interest in children's welfare in recent years, there has been a lack of consideration for those with special needs or health conditions such as autism spectrum disorder (ASD). Both children with ASD and neurotypical children may be affected by low self-esteem, poor physical condition, or psychological distress at school, which can affect their quality of life. It is therefore important for children and young people to have their quality of life measured and understood. While, for the Arab world, including Saudi Arabia, there has been the translation of health-related quality of life tools, there is a need to ensure their validity compared to the original English language versions. In light of this need, this paper presents the development and application of the KIDSCREEN-52 method to measure the quality of life for children with ASD and neurotypical children in schools in Saudi Arabia. A quantitative approach was employed to achieve the development of the method consisting of instrument translation and the standardized assessment of the quality of life for Saudi pupils. This developed method was found to independently and analytically assess the quality of life in Saudi pupils. The results from the application of the developed instrument revealed that although children without ASD rated their quality of life higher than those with ASD, overall, most Saudi Arabian students with ASD enjoy a reasonable quality of life. The findings of this study should be of interest to educators and individuals working with and on behalf of school-aged children and young people in foreign language settings where the application of development instruments could reveal the health-related quality of life.

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1. Introduction

The relative physical, psychological, social, and cultural advantages of improving its related determinants mean that quality of life has become an important consideration in health and social sciences in recent years (Sinha, 2019). Although there has been a substantial increase in the amount of research on health, education research has not yet adapted to the variables that measure the quality of life and has not designed interventions to improve the quality of the student experience (Gheorghe et al., 2016). The research that has been conducted on this topic to date does not make it clear whether improving educational outcomes has any impact on quality of life (Steinberg and Down, 2020). Higher

education levels are associated with improved quality of life (Moroz et al., 2016), which provides some promising preliminary data to support the role of quality-of-life screening in schools.

As a result of the contributions of health sciences to the current understanding of the health-related quality of life, Saudi researchers have begun to examine the impact of screening students for health issues within the education system. Whilst no evidence has been found in the literature to determine the effectiveness of such attempts, recent translations of health-related quality of life tools into Arabic have been relatively successful (Al Sayah et al., 2013). Much work still needs to be done to adapt these instruments for young people and ensure that they maintain the same validity and reliability rating as the English version (Danial-Saad et al., 2012) and there is a need to further investigate the measurement properties of Arabic language PROMs measures before there can be routine use in clinical practice (Alaqeel et al., 2021).

Cultural and social differences between western contexts and Saudi Arabia mean that different

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<https://doi.org/10.21833/ijaas.2022.07.001>

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instruments are required for the Saudi school population (Al Sayah et al., 2013). Several forms of health-related quality of life assessment tools have been criticized for being invalid, and this is exacerbated when they are translated into other languages (Griffiths et al., 2010). Similarly, some health-related quality of life assessment tools for adults have been adapted, leading Griffiths et al. (2010) and Fairclough (2010) to criticize the extent to which they are suitable for assessing the quality of life in young people. To measure health-related quality of life in Saudi Arabian children and adolescents, researchers must ensure that their instruments truly capture the construct they are trying to measure.

Measuring the health-related quality of life can show how ASD has an impact on daily functioning and those with ASD have a poor quality of life scores (Menezes and Mazurek, 2021). Many of the issues associated with current health-related quality of life instruments may be further compounded when screening for this construct in children with autism spectrum disorder (ASD) (Kuhlthau et al., 2010). Research on the ability of children with ASD to report their quality of life accurately and reliably is inconclusive, and further research is needed before educational professionals can confidently screen for these outcomes in schools (Lee et al., 2008; Kuhlthau et al., 2010). In fact, according to Meral and Fidan (2015) measures for health outcomes for children with ASD have received little attention in the literature. Assessing the quality of life for people with ASD is complicated because it is affected by several factors. People might rate their health-related quality of life differently when completing the form in the presence of a parent- or guardian-proxy versus independently, suggesting that existing instruments may be insufficient (Potvin et al., 2015). It is well known that children and adolescents with ASD and their families have a reduced quality of life (Potvin et al., 2015). Nevertheless, the degree to which this construct can be improved is of great importance to educational professionals. To effectively screen for this variable, it is important to use an instrument that is effective (Potvin et al., 2015). Conditions in state schools in the Arab world are to some extent ambiguous due to under-reporting. The design of instruments specifically for children with ASD may help shed light on the best possible interventions for students with ASD in the Arab education system.

The issues described above suggest that screening for health-related quality of life is a worthwhile endeavor for Saudi educators. There is still much work to be done before these professionals can confidently identify the determinants and consequences of health-related quality of life in the school population. This need is even greater for children and adolescents with autism. The lack of environment- and demographic-specific tools, potential language and cultural barriers when using adaptive tools, and the reliable completion of subjective quality of life self-

assessments for children with ASD, are some of the areas where more research is needed.

2. Methods

A group of students from Saudi schools participated in this study. Participants were recruited by selecting schools listed in an Education Ministry database of Saudi schools in particular locations (Jeddah, Riyadh, and Makkah). For the initial standardization phase of this study, children from multiple schools and a special care center located within the community that specializes in working with children with ASD were recruited.

Convenience sampling was used to recruit 341 children without ASD and 51 students with ASD between the ages of eight and 18. Although this sampling method is not ideal in terms of the external validity and universality of the results obtained, as it was necessary to select participants who met specific inclusion criteria (namely school children with ASD and 8-18-year-old schoolchildren without ASD), it is considered that this alternative sampling method was reasonable. The study used KIDSCREEN-52 tools, which have been proven to have excellent reliability and have been adapted into more than 10 different languages, each with sufficient reliability and validity scores (Ravens-Sieberer et al., 2005). It can therefore be argued that this study overcomes the limitations related to sample size and representativeness. Students with ASD were recruited by contacting local institutions and special education programs that specialize in working with this special needs group.

An assessment of the sample for both ASD and non-ASD respondents and their profiles is shown below. This consists of background information, such as the type of school the child attends, family income, the city where the answer was obtained, and the gender of the child. A summary of these raw data is presented in the following frequency distribution below (Table 1).

2.1. Measures

The KIDSCREEN-52 instrument was validated by collecting data from 3,000 children from European schools. The results of this study show that the test has good reliability and validity. This research used statistics about the internal consistency of responses gathered from KIDSCREEN-52 surveys conducted in Germany. The average Cronbach's alpha for surveys published by KIDSCREEN-52 was between 0.77 and 0.9. The study found that, with some minor exceptions, students with ASD had on average similar reliability statistics to their non-ASD counterparts (see Table 2).

2.2. Statistical analysis

Principal component analysis (PCA) is applied to data collected through structured questionnaires

based on [Ravens-Sieberer et al. \(2005; 2010\)](#) and distributed to Saudi Arabian students. [Ravens-Sieberer et al. \(2005; 2010\)](#) suggested that quality of life can be assessed according to ten categories, specifically: physical health, mental health, mood and

emotions, self-awareness, independence, parental relationships and family life, financial resources, social support and peers, and the environmental and social acceptance of the school.

Table 1: General information about ASD and non-ASD children

		Children with ASD		Children without ASD	
		Frequency	Percent	Frequency	Percent
School	Primary School 5-11 years	26	51	193	56.6
	Secondary School 12-18 years	25	49	148	43.4
	Total	51	100	341	100
Income	Low	2	3.9	42	12.3
	Medium	35	68.6	15	4.4
	High	14	27.5	284	83.3
	Total	51	100	341	100
City	Al-Riyadh	12	23.5	52	15.2
	Jeddah	15	29.4	264	77.4
	Makkah	24	47.1	25	7.3
	Total	51	100	341	100
Gender	Boy	31	60.8	99	29
	Girl	20	39.2	242	71
	Total	51	100	341	100

Table 2: Reliability statistics

Dimension	Reliability Statistics of children with ASD		Reliability Statistics of non-ASD children	
	Cronbach's Alpha	N of Items	Cronbach's Alpha	N of Items
Physical Activities and Health (Physical Well-being)	0.824	4	0.823	4
Feelings (Psychological Well-being)	0.792	4	0.827	6
General Moods (Moods and Emotions)	0.739	7	0.931	7
About Your-self (Self-Perception)	0.778	3	0.871	3
Free Time (Autonomy)	0.846	5	0.843	5
Family and Home Life (Parent Relationships & Home Life)	0.914	6	0.859	6
Money Matters (Financial Resources)	0.858	3	0.876	3
Friends (Social Support and Peers)	0.953	6	0.864	6
School and Learning (School Environment)	0.96	6	0.858	6
Bullying (Social Acceptance)	0.773	3	0.865	3

Principal component analysis shows how data collected using a structured questionnaire fits these ten categories. The KIDSCREEN-52 questionnaire contains 52 questions related to the quality of life of

children with and without ASD. Principal component analysis was used to estimate the number of factors for which these 52 questions apply (see [Table 3](#)).

Table 3: Total variance explained (students with ASD)

Component	Initial Eigenvalues			Extraction Sums of Squared Loadings		
	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %
1	21.515	41.374	41.374	21.515	41.374	41.374
2	4.394	8.449	49.823	4.394	8.449	49.823
3	3.58	6.885	56.709	3.58	6.885	56.709
4	3.471	6.675	63.383	3.471	6.675	63.383
5	3.043	5.852	69.235	3.043	5.852	69.235
6	1.933	3.716	72.951	1.933	3.716	72.951
7	1.782	3.427	76.378	1.782	3.427	76.378
8	1.317	2.532	78.911	1.317	2.532	78.911
9	1.175	2.26	81.171	1.175	2.26	81.171
10	1.14	2.193	83.364	1.14	2.193	83.364

The ten factors together explain more than 83% of the total variance in the responses of students with autism. However, compared with the dominant factors, the explanatory power of the last five factors is quite weak. To test which questions belong to which factors, factor loads were calculated based on the rotation pattern matrix ([Muijs, 2011](#)) using the direct Oblimin method in SPSS for rotation. [Ravens-](#)

[Sieberer et al. \(2005; 2010\)](#) also applied this type of rotation because it allows hypothetical factors to be correlated ([Davies and Hughes, 2014](#)). This assumption had to be accounted for because it is expected that people's emotional and mood state would affect their mental and physical health. Other methods of rotation (such as Varimax) do not allow particular assumptions ([Burns and Burns, 2008](#)).

The output presented was not just a structured matrix of factors, but also a pattern matrix. The latter was analyzed because it showed the inherent contribution of each factor, while the structured matrix showed a meaningful cumulative contribution only under the assumption that the factors were uncorrelated, which was not

demonstrated (Bryman and Cramer, 2009). The size of the pattern matrix is too small to allow for its efficient loading. To evaluate the relationship between the ten factors that describe the quality of life of students with autism, the following correlation coefficients between factors were estimated (see Table 4). Table 5 shows the total variance explained.

Table 4: Correlations between components (students with ASD)

Component	Autonomy	Psychological Wellbeing	Mood and Emotions	Physical Wellbeing	Social Acceptance	Social Support and Peers	Parent Relationships and Home Life	Financial Resources	Self-Perception	School Environment
Autonomy	1									
Psychological Wellbeing	0.336	1								
Mood and Emotions	0.514	0.388	1							
Physical Wellbeing	0.483	0.323	0.446	1						
Social Acceptance	0.209	-0.252	0.309	0.429	1					
Social Support and Peers	0.449	-0.294	0.527	0.367	0.382	1				
Parent Relationships and Home Life	0.267	0.336	0.242	0.458	0.335	-0.267	1			
Financial Resources	0.519	-0.285	0.338	0.301	0.326	0.237	-0.268	1		
Self-Perception	0.368	0.264	0.444	0.399	0.31	0.368	0.279	-0.238	1	
School Environment	-0.124	0.352	0.35	-0.173	0.324	-0.216	0.376	0.311	-0.127	1

Table 5: Total variance explained

Component	Initial Eigenvalues			Extraction Sums of Squared Loadings		
	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %
1	13.452	27.454	27.454	13.452	27.454	27.454
2	6.709	13.692	41.146	6.709	13.692	41.146
3	2.351	4.798	45.943	2.351	4.798	45.943
4	2.131	4.348	50.292	2.131	4.348	50.292
5	1.877	3.83	54.122	1.877	3.83	54.122
6	1.808	3.689	57.811	1.808	3.689	57.811
7	1.354	2.764	60.575	1.354	2.764	60.575
8	1.195	2.44	63.015	1.195	2.44	63.015
9	1.099	2.243	65.258	1.099	2.243	65.258
10	1.058	2.16	67.418	1.058	2.16	67.418

Together, the components account for approximately 67.4% of the total variance of the responses from children without ASD. The data in Table 6 shows that there is a significant association between physical activity and health and well-being. This result shows that the healthier the children without ASD, the better they feel. Children who do not have ASD and feel good about themselves tend to also feel good while they are in school. Furthermore, the freer time children without ASD have, the better they feel. Such findings, if not addressed, have serious implications for the future. To enjoy school and have good relationships with teachers, parents should treat their children well at home.

3. Findings and discussion

Measuring quality of life is difficult because it requires several different aspects to be considered. Ravens-Sieberer et al. (2005; 2010) suggested that quality of life should be assessed using ten categories. This study examined how the ten dimensions of health-related quality of life relate to

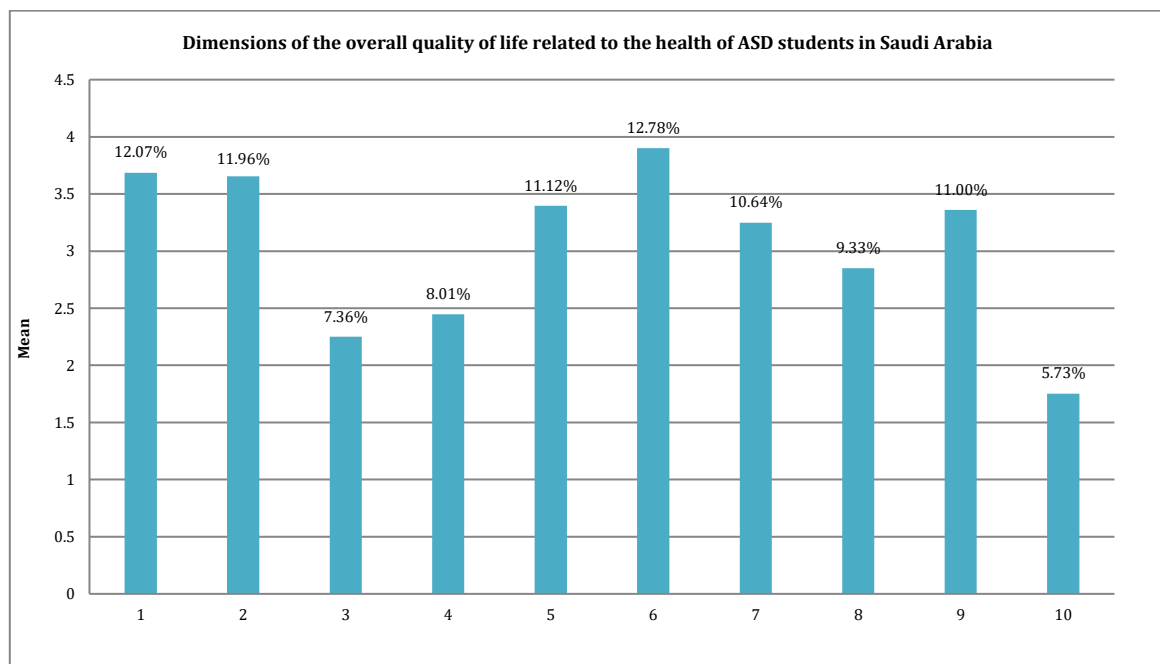
students in Saudi Arabia, whether or not they had ASD.

Self-perception assesses how students perceive themselves. This study examined whether the respondent's perception of their physical appearance was positive or negative. It found that students with autism spectrum disorder rated themselves as the second-lowest among the dimensions. Fig. 1 shows that only 8.11% of the quality of life is accounted for by subjective perceptions. This is surprising because data from Europe and other parts of the world show that this dimension is robust, being ranked as the second-highest (10.18%) in terms of its contribution to the quality of life in Europe (Ravens-Sieberer et al., 2005; 2010). Al-Shammari et al. (2021) said there are cultural influences in Middle East countries, and in Saudi Arabia specifically, that affect the quality of life scores. Al-Mubarak et al. (2011) argued that as the cultural traditions of Saudi society differ from those in the Western world, determinants, and influences on the quality of life may also be different. There is some evidence to suggest that in Saudi society, family, social and socioeconomic status play a greater

role in the quality of life than individual psychological and emotional factors (Al-Kandari and Gaither, 2011).

Table 6: Correlations between components

Component	Physical Activities and Health	Feelings	General Mood	About yourself	Free time	Family and Homelife	Money Matters	Friends	School and Learning	Bullying
Physical Activities and Health	1									
Feelings	0.648	1								
General Mood	-0.158	-0.179	1							
About yourself	0.153	0.247	0.482	1						
Free time	0.453	0.53	-0.034	0.377	1					
Family and Home life	0.472	0.593	-0.274	0.167	0.505	1				
Money Matters	0.319	0.414	-0.074	0.212	0.513	0.519	1			
Friends	0.404	0.485	-0.061	0.229	0.565	0.405	0.485	1		
School and Learning	0.405	0.49	-0.204	0.151	0.419	0.516	0.466	0.469	1	
Bullying	0.058	0.077	0.483	0.514	0.264	0.055	0.096	0.204	0.156	1



1: Physical; 2: Psych; 3: Mood; 4: Self perc; 5: Free time; 6: Family; 7: Money; 8: Friends; 9: School; 10: Bully
Fig. 1: Dimensions of the overall life related to the health of ASD students in Saudi Arabia

An additional noteworthy finding is that the self-perception of students with ASD was higher than the self-perception of those without ASD in Saudi Arabia. Although it was low in both groups, the unexpected finding from the data may reflect positive attitudes towards people with disabilities in Saudi Arabia. In Saudi Arabia, many studies have reported that people show positive attitudes toward individuals with disabilities for example (Al-Rubiyea, 2010). A possible explanation for this might be that Saudi Arabian culture is based on religious beliefs.

The second research topic is devoted to parental relations and family life. This is an important issue for all children, including those who do not have ASD. It is important for children to spend time with their parents, which often leads to a significant improvement in the child's quality of life. In today's highly competitive world, both parents are often busy going out to work, and many people feel that

they do not have enough time to spend time with their children (Cohn, 2006). This study found that children with ASD ranked their parents' relationship as the most important dimension of their life, and the school environment as the second most important. This result was unexpected because data from Europe and the rest of the world showed that this dimension is robust, but not as strong as that found in this research.

This positive outcome of Saudi Arabia's parent-child relationships may help enhance the value of broader beliefs about Saudi Arabian families and thus family life. Even those who do not participate in the practice of faith still participate in rituals based on faith and society as a whole. These values affect attitudes, behaviors, and interactions with others in society (Al-Rubiyea, 2010). The family is given advice and guidance on how to behave in a relationship. Values also underline the role, importance, and

responsibility of parents towards their children. Parents are expected to take on all of their post-birth responsibilities, such as taking care of their child's health, dressing and feeding them, and showing love. These values emphasize the role of parents and help prepare them to fulfill their responsibilities towards their children, which in turn has a positive effect on the parent-child relationship. With reference to disability, people in Islamic cultures such as Saudi Arabia, believe that it has moral significance. Many families believe that the presence of a disabled child in the family is a test of faith (Bazna and Hatab, 2005). This understanding of disability and its causes in the context of belief-based values can lead to a positive view of children with disabilities in the family, and these positive views of disability can therefore be regarded as improving the parent/child relationship (Al-Aoufi et al., 2012).

The third factor investigated was the school environment, as this can be an important issue for children with ASD. This everyday environment needs to be very friendly to enable them to adapt easily and feel comfortable. A third interesting finding from the raw data relates to schools and studies in Saudi Arabia, showing that quality of life is good. Nevertheless, such a conclusion is not in line with those of other European researchers (KIDSCREEN-52). Lee et al. (2008) found that children with ASD are more likely to miss school and less likely to participate in community activities than children without ASD. Furthermore, previous studies have shown that students with ASD find it difficult to make friends and communicate with teachers at school (Kasari et al., 2011). Moreover, teachers sometimes show a less positive attitude towards educating students with ASD, which can adversely affect them. This is similar to the opinions of fellow students about their peers with ASD.

It is possible that recent improvements in the education system in Saudi Arabia have contributed to positive outcomes in the school environment. For instance, the Saudi education system supports learners with disabilities (Alquraini, 2011; Alnahdi, 2020). The programs help students overcome their academic challenges, resulting in an adapted program of care and support for such learners. In addition, the Saudi education system offers many services and programs for students with ASD in mainstream settings, including adapted teaching methods, facilities, resources and equipment, and support services and specialists.

Furthermore, the attitudes of teachers toward students with disabilities may be another reason for the positive results of this research. For example, a study by Al-Faiz (2006) found that most elementary school teachers have a positive attitude towards inclusive education for students with ASD. Jones (2013) believed that the value of adult-child interaction comes directly from adults, showing that the opinions, ideas, and experiences of adults (teachers) motivate students with special needs to be accepted and taught together with their peers in mainstream classrooms. These findings could be of

interest to the education sector and those who work with and on behalf of students and young people.

Quality of life is also affected by financial resources. Most Saudi Arabian participants in this study indicated that they have enough money to cover expenses compared to friends. However, it should be noted that the sample in this study was largely categorized as middle or upper class, as the regions in Saudi Arabia where participants lived are considered to be well-positioned financially. In contrast, Sharpe and Baker (2007) found that families of students with autism had lost their future financial security and some even went bankrupt. Students with ASD may therefore not be able to enjoy the same quality of life as other students. Financial support in contemporary times is indeed very important. A person needs money to realize their dreams and to obtain the basic necessities for life. Students may be young and inexperienced, with little understanding of the importance of money in their future, but they can still enjoy quality things without compromise.

Parents of children with ASD often face different time and financial pressures than parents of children who are not on the spectrum. Specialized childcare is expensive, and the duration of care often has to be longer than that required for children without ASD. In the United States, Sharpe and Baker (2007) cited the example that whilst mainstream schools may offer language and speech therapy, families often cannot afford the high cost of behavioral interventions for each child with ASD, and even if they could, the school would not have the necessary staff. Montes and Halterman (2008) found that parents of children with ASD have to spend a greater percentage of their income on their children. Many parents must stop or reduce the number of hours they work in order to care for their children with ASD (Kogan et al., 2006). Some parents cannot participate in psycho-educational early intervention programs for many reasons, such as long waiting times (Birkin et al., 2008). Parents of students with ASD need to spend around 100 hours a year supporting their children. As a result, the ASD family is likely to face financial problems, which can place additional pressure on them (Kogan et al., 2006). However, this does not appear to be the case in the Saudi Arabia sample.

4. Conclusion

This study successfully developed and validated the KIDSCREEN-52 tool in the Arabic language to examine Saudi pupils and young people with ASD perceptions of health-related quality of life. The results showed that cultural factors play a role in the perception of health-related factors where culture manifests as religious beliefs and the important role of parents and the family unit, generally having a positive effect on perceptions. As such, this study contributes to a better understanding of students' perceived health to help determine whether the population is at risk. The information gathered from

the survey is an important source of evidence for the provision, policy, and practice of health services for children and young people at a national and international level. Through validation of the developed instrument, this study also encourages the validation and use of KIDSCREEN-52 in other language contexts.

Compliance with ethical standards

Conflict of interest

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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