

## איכות החיים של מתבגרים ובוגרים צעירים עם שיתוק מוחי בשלוש קהילות במזרח התיכון

Netta Harries<sup>1</sup>, Ibtisam Nammourah<sup>2</sup>, Muhammed Al-Jarrah<sup>3</sup>, Akram Amro<sup>4</sup>, Simona Bar-Haim<sup>5</sup>

<sup>1</sup> Assaf-Harofeh, Human Motion Analysis Laboratory, Zerifin, Israel

<sup>2</sup> Jerusalem Princess Basma Center for Disabled Children, Department of Physical Therapy, East Jerusalem

<sup>3</sup> Jordan University of Science and Technology, Faculty of Applied Medical Sciences, Irbid, Jordan

<sup>4</sup> Al-Quds University, Department of Physical Therapy, Abu Dees, Palestinian Authority

<sup>5</sup> Dr. Bar-Haim, PhD, PT, Faculty of Health Sciences, Ben-Gurion University of the Negev, Israel;  
e-mail: barhaims@bgu.ac.il

בכל התחומים היה מעל 50% - (במידה בינונית עד טוב). המשתתפים בדרגת GMFCS III דיווחו על איכות חיים כללית, בריאות פסיכולוגית וקשרים חברתיים גבוהים יותר מאלה בדרגת GMFCS II. בתחום הקשרים החברתיים בנים דיווחו על איכות גבוהה יותר מבנות. משתתפי הקבוצה הבוגרת יותר (18 - 23 שנים) העריכו את מצב בריאותם הפיזית גבוה יותר מאלה בקבוצה הצעירה (13-17 שנים). ציון נמוך ניתן לתחום הקשרים החברתיים בקרב הבנות ובמיוחד בקרב המשתתפים בדרגת GMFCS II. המשתתפים מישראל וירדן דיווחו על איכות חיים כללית ובריאות פיזית גבוהה יותר מאשר המשתתפים מהרשות הפלסטינית. לא נמצא הבדל בהערכת הקשרים החברתיים בין המרכזים.

**מסקנות:** אוכלוסית מתבגרים ובוגרים צעירים עם שיתוק מוחי, זקוקה לעזרה מיוחדת ביצירת הזדמנויות ועידוד פעילות פנאי וליצירת קשרים חברתיים. דגש מיוחד יש לתת להעצמה נשית.

**מילות מפתח:** איכות חיים, WHOQOL-BREF, שיתוק מוחי, מתבגרים ובוגרים צעירים

**רקע:** בעת תכנון טיפול מכל סוג שהוא עבור אנשים עם מגבלות תפקודיות, יש לתת את הדעת, בראש ובראשונה, לדרך שבה אפשר לשפר את איכות חייהם. איכות חיים היא מושג סובייקטיבי ואנשים שונים מעריכים את איכות חייהם לפי מדדים שונים. נמצא כי איכות חיים נמצאת בקשר ישיר עם מצבי בריאות פיזיים ופסיכולוגיים כמו גם ביצירת קשרים חברתיים ותנאי הסביבה בה חי האדם.

**מטרות:** לבדוק את התפיסה האישית של איכות החיים אצל מתבגרים ובוגרים צעירים עם שיתוק מוחי בשלוש קהילות במזרח התיכון. מדידת איכות החיים לפי התפיסה הסובייקטיבית של המטופל חשובה להערכה ותכנון התערבויות שיקומיות.

**שיטות:** השאלון WHOQOL-BREF מולא על ידי 51 מתבגרים ובוגרים צעירים עם שיתוק מוחי. טווח גילים 13-23 שנים. מדגם נוחות משלושה מרכזים - מירדן (20), הרשות הפלסטינית (22) וישראל (9). במחקר השתתפו 29 בנים ו-22 בנות. דרגת התפקוד Gross Motor Function Classification System GMFCS II-33, GMFCS III-18 השאלון מעריך את איכות החיים הסובייקטיבית של האדם ומתחשב במטרות, בציפיות, בנורמות ובמסגרת התרבותית שהיחיד חי בה. שאלון זה מודד ארבעה תחומים הקשורים לאיכות חיים: בריאות פיזית, בריאות פסיכולוגית, קשרים חברתיים וסביבה. כמו כן הוא מספק הערכה כללית של איכות החיים והבריאות של האדם.

**תוצאות:** ציון שאלות איכות חיים כללית ושביעות רצון ממצב הבריאות היה "טוב". הציון הכולל הממוצע בתשובות

## Quality of life of adolescents and young adults with Cerebral Palsy in three communities in the Middle East

Netta Harries<sup>1</sup>, Ibtisam Nammourah<sup>2</sup>, Muhammed Al-Jarrah<sup>3</sup>, Akram Amro<sup>4</sup>, Simona Bar-Haim<sup>5</sup>

<sup>1</sup> Assaf-Harofeh, Human Motion Analysis Laboratory, Zerifin, Israel

<sup>2</sup> Jerusalem Princess Basma Center for Disabled Children, Department of Physical Therapy, East Jerusalem

<sup>3</sup> Jordan University of Science and Technology, Faculty of Applied Medical Sciences, Irbid, Jordan

<sup>4</sup> Al-Quds University, Department of Physical Therapy, Abu Dees, Palestinian Authority

<sup>5</sup> Dr. Bar-Haim, PhD, PT, Faculty of Health Sciences, Ben-Gurion University of the Negev, Israel; e-mail: barhaims@bgu.ac.il

### Abstract

**Introduction:** While planning intervention and therapy for people with disabilities, the guiding thought should be to improve their quality of life (QoL). QoL is a subjective concept incorporating the individual's physical health, psychological state, social relationships and the environmental conditions.

**Aim:** To determine the perceptions of the QoL of adolescents and young adults with cerebral palsy (CP) in three communities in the Middle East. Measuring QoL perceptions is important in evaluating and planning rehabilitation interventions.

**Method:** The WHOQOL-BREF questionnaire was self-reported by 51 teenagers and youths with CP, a convenience sample from three communities in Jordan (n=20), the Palestinian Authority (PA) (n=22) and Israel (n=9). 29 males. Age range for the sample was 13-23

yrs, of Gross Motor Function Classification System (GMFCS) II n=33 and III n=18.

The questionnaire contains 26 items and addresses four QoL domains: physical health, psychological health, social relationships and environment. Two additional items measure overall QoL and general health.

**Results:** Overall QoL and general health were "good". Average domain scores were at or above 50%, considered "acceptable to good". Those at the GMFCS III reported higher overall QoL in the psychological and social relations domains than did those at level II. The social domain score was higher for male than for female participants. The older group (18-23 yr) reported a better physical domain score than did the younger group (13-17 yr). The social relationships scores of the older group and of the females and were especially low among the higher mobility group (GMFCS II). The overall QoL (Q1) was higher among participants in Israel than in Jordan or the PA. The physical domain scores of participants in Israel and in Jordan were higher than those in the PA. The psychological domain and environment domain scores in Israel were higher than those of participants in Jordan or the PA.

**Conclusions:** This population of youth with CP needs particular help in creating opportunities and encouraging recreational and social encounters to develop peer relationships. Special emphasis should be given to empowering females in the Middle East.

**Key words:** quality of life, WHOQOL-BREF, cerebral palsy, adolescents, young adults

## Introduction

Assessing the Quality of Life (QoL) of the general population and of individuals with health impairments at various ages is important for researchers and therapists. Health status measurements have recently become more sophisticated, beyond traditional health indicators such as mortality and morbidity. These measures include the impact of disease and impairment on daily activities, behavior and functional status. Quality of life has been described as "the missing measurement in health". The World Health Organization (WHO) has defined QoL as "Individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns".<sup>1</sup> Quality of life is a broad-ranging concept incorporating the individual's physical health, psychological state, level of independence, social relationships, personal beliefs and relationship to the environment. It is a multidimensional concept incorporating the individual's perception of these and other aspects of life.<sup>2</sup>

The WHO identifies adolescence as the period of growth and development that occurs after childhood and before adulthood, between ages 10 and 19 yrs.<sup>3</sup> This transitional stage incorporates many physical, mental (emotional and intellectual) and social changes: this is a unique stage in the individual's development, during which one faces important personal challenges. The aforementioned age group can be considered to include also the stage of early adulthood, during which QoL vary according to the mix of overlapping indices (legal, maturational, occupational, sexual, emotional, employment status, etc.). The definition of life stages also depends on whether developmental or socialization status are considered. Young adult years are best described by various developmental tasks and are dependent on cultural traditions.<sup>4</sup>

Cerebral palsy (CP) describes a group of permanent disorders of movement and posture, manifested as activity limitations, which are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of CP are often accompanied by disturbances of sensation, perception, cognition, communication and behavior. Epilepsy, secondary musculoskeletal problems and pain are often also present.<sup>5</sup> The promotion of health and well-being is the primary focus of rehabilitation services, but intervention goals are often predominantly directed at improving only motor function and activities of daily living. The measurement of QoL of adolescents and young adults with CP is necessary in order to identify important issues, apart from remediation of their impairments.

The WHOQOL-BREF tool<sup>6</sup> was developed, tested and found suitable for measuring QoL in healthy and ill populations.<sup>7</sup> Studies have shown that the questionnaire scores discriminate well between sick and healthy individuals. Skevington and McCrate<sup>8</sup> have confirmed that sick individuals have a lower QoL. In one study, the only domain in which adolescents with CP had lower QoL scores than those of the general population was the domain of social support and peer relationships.<sup>9</sup> In that study, impairment type and severity had an impact on QoL; e.g., impaired walking ability was associated with reduced autonomy. Health organizations consider QoL and participation (defined as involvement in life situations) as important outcome measures following interventions for children with impairments.<sup>10</sup>

Many studies around the world have measured QoL of people with diverse disabling conditions, including CP. However, there is a lack of information on adolescents and young adults with CP in the Middle East. Therefore, the aim of this study was to determine the perceptions of QoL of adolescents and young adults with CP in three communities in the Middle East, so that subsequent

intervention approaches could more closely match their needs and expectations.

## Methods

This study is part of a project to evaluate therapeutic approaches to improve the daily life of young populations with disabilities related to brain abnormalities congenital or acquired at an early age. It is part of a multicenter project entitled: The Middle East “Stepping forward” (MESF), NIH registration number NCT01466296. Data collection began in October, 2010.

### Participants and procedures

A convenience sampling method was used to recruit participants. Home-dwelling participants treated at rehabilitation and sports centers for the disabled were recruited by attending physiotherapists in Jordan, the Palestinian Authority (PA) and Israel. Initial telephone interviews determined potential eligibility. The participants resided within a limited area around each center. The center in Jordan recruited participants from the Irbid area in the north of the country, participants from the PA came from the Hebron area and Jerusalem, and those from Israel were from the country's central region. Suitable candidates were then invited for personal interviews. After receiving a detailed explanation of the study, a written informed consent was signed by the participants, their parents or guardians if they agreed to participation. Approval for this study was granted by the ethical review boards of the participating centers: Assaf Harofeh Medical Center Israel, Jerusalem Princess Basma Center for Disabled Children, Palestinian Authority and Jordanian University of Science and Technology in Irbid, Jordan.

Inclusion criteria were as follows: (a) diagnosis of CP, predominantly spastic bilateral type, (b) age: 13 - 23 yrs, (c) Gross Motor Function Classification System (GMFCS) levels II and III, (d) no orthopedic surgery or

other tone reduction intervention in the last six months, (e) living at home with family and (f) can comprehend and answer the QoL questions. Exclusion criteria were as follows: (a) candidates for orthopedic surgery or other tone reduction procedures (e.g., Botulin Toxin injections) in the next 6 months, (b) uncontrolled convulsions, if epileptic or (c) reported lower extremity injuries in the last six months.

Seventy eight adolescents and young adults with CP were contacted and interviewed by phone: 26 from Jordan, 28 from the PA and 24 from Israel. Of these 51 met the criteria and agreed to participate: 20 from Jordan (12 males and 8 females; 4 at GMFCS III and 16 at II), 22 from the PA (15 males and 7 females; 8 at GMFCS III and 14 at II) and nine from Israel (2 males and 7 females; 6 at GMFCS III and 3 at II).

### Instruments

The generic version of the WHOQOL-BREF questionnaire<sup>11</sup> was self-reported by participants at the three centers. This popular instrument was developed for cross-cultural comparisons of QoL and is available in many languages. The questionnaire has a high reliability and validity and has been found to have “very good to excellent” psychometric properties.<sup>8,12,13</sup> This self-administered questionnaire is a short version of the WHOQOL 100-item scale<sup>12</sup> which consists of two general questions, overall quality of life (Q1) and general health (Q2) and 24 items in four domains. Each domain includes several aspects/facets: Physical health domain has 7 questions about pain, discomfort, energy, fatigue, sleep and rest; in the psychological domain there are 6 questions about feelings, appearance, self-esteem, memory and concentration; in the domain of social relations there are 3 questions about relationships, social support and sexual activity; and in the domain of environment there are 8 questions related to safety, home environment, finances, leisure, transport and social care. The response options range from 1 “very

dissatisfied/very poor” to 5 “very satisfied/very good”, as perceived over the preceding two weeks.

A study found that healthy people typically evaluated their physical and social QoL as “very good” and their environmental and psychological QoL as “good,” and that people with illnesses or a disability typically reported their environmental and social QoL as “good” and their physical and psychological QoL as “acceptable.”<sup>8</sup> These results provide evidence of the discriminating validity of the WHOQOL-BREF. A study in 2009 demonstrated that adolescent participants with CP considered their QoL as an interaction between intrinsic and extrinsic factors.<sup>14</sup> The predominant theme involved a relationship between personal interests and preferences (intrinsic) and opportunities to participate in age-appropriate and leisure activities (extrinsic). Apparently, an opportunity to participate in attractive activities affects an individual’s perceived QoL and this perception was consistent regardless of the level of motor impairment.

The Hebrew version was used in Israel and the Arabic version in Jordan and the Palestinian Authority. The generic version of WHOQOL-BREF was used in this study, because no adolescent version was available. It was self-reported, with occasional assistance from the interviewer, who read items aloud, because of literacy or disability issues. Parents of minors or family members were present with the participant’s permission. Raw scores were calculated manually for domains and converted to a percentage. Instructions for percentage calculations of the domain scores permit omission of one facet in the social relations domain.

The GMFCS E&R (age related) is a 5-level classification system that describes the gross motor function of children and youths with CP, on the basis of their self-initiated movements with particular emphasis on sitting, walking, and wheeled mobility.<sup>15</sup> Distinctions between

levels are based on functional abilities, the need for assistive technology, including hand-held mobility devices (walkers, crutches, or canes) or wheeled mobility. For example, at GMFCS level II, individuals walk with limitations, whereas at GMFCS level III individuals walk using hand-held mobility devices and at school they may self-propel a manual wheelchair or use powered mobility.

### Data analysis

Tests for normality of the distribution of scores of the four domains (%) and in Q1 and Q2 indicated that scores for domain 3, Q1 and Q2 were not normally distributed. Therefore, the Mann-Whitney U test and Kruskal-Wallis non-parametric tests were conducted for these measures. Differences between Q1 and Q2 and domain scores (%) were analyzed using one-way-ANOVA tests, for the following groupings: place of origin (Jordan, the PA and Israel), age subgroups (13-17, 18-23yrs), gender (male, female) and GMFCS levels II and III. The level of significance was assumed to be  $p < 0.05$ , with data reported as means ( $\pm$ SD). Statistical analyses were performed using SPSS version 22.0.

## Results

The sample consisted of 51 adolescents and young adults with CP: 29 males, 22 females, from the three centers, ranging in age from 13 to 23 yr. Their mobility by GMFCS indicated that 33 were at level II and 18 at level III (Table 2). Thirty-three used no walking aids and 18 used sticks, crutches or walkers. The WHOQOL-BREF mean scores for all participants are shown in Table 1. The overall QoL and general health was “good,” as evidenced by mean scores of 3.5 and 3.4 for Q1 and Q2. Domain scores were 50% or above, indicating that QoL in the four domains was “acceptable to good”.

Some WHOQOL-BREF domains, Q1 and Q2 scores were significantly different between centers, as shown in Figure 1. The overall QoL (Q1) was higher in Israel than in either Jordan or the PA. The physical domain scores in both Israel and Jordan were higher than those indicated by participants in the PA, and the psychological and the environmental domains scores in Israel were higher than in Jordan or the PA. Subgroups scores are presented in Table 2. The older group reported higher scores on physical condition than did the younger group, and in the domain of social relationships, the younger group reported higher scores than did the older group. Comparisons by gender indicated a significant difference in the social relations domain, where males scored higher than females. Participants in GMFCS level III scored higher than those at level II in overall QoL and in the psychological and social domains. The same trends were apparent in general health and the environment domain, but were not significant. The question about sexual relations was the most problematic. Twenty-five participants, 10 of the males (34%) and 15 of the females (68%), did not answer this question. Also, the question related to “work capacity” was not answered by seven (14%), with six of these in the younger group.

**Table 1: Anthropometrics and WHOQOL-BREF measurements of participants with Cerebral Palsy (N=51)**

Characteristics	Mean	SD	Range
Age (yrs)	17.7	2.8	13.0-23.3
Height (cm)	158	10	125-178
Weight (kg)	54.0	12.1	30.1-81.7
BMI* (kg/m <sup>2</sup> )	21.6	4.0	15.4-32.8
Q 1 - Overall Quality of Life	3.47	1.03	1-5
Q 2 - General Health	3.35	0.96	1-5
Domain 1 - Physical Health	55.0	14.8	19-81
Domain 2 - Psychological	60.3	18.5	19-94
Domain 3 - Social Relationships	49.6	21.8	6-100
Domain 4 - environment	58.2	18.8	19-100

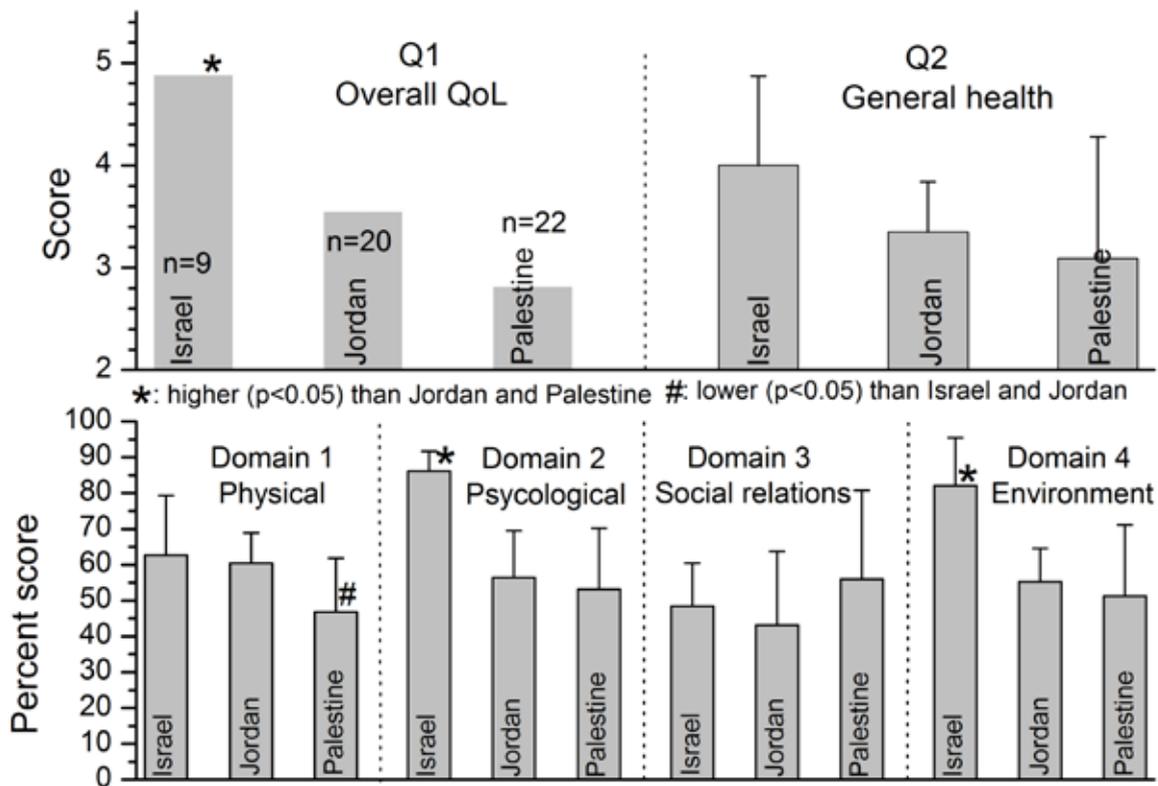
\*BMI - body mass index

**Table 2: Scores of WHOQOL-BREF Measurements by Age, Gender and GMFCS (N-51)**

Variable	Age group yrs	Mean (SD)	p-value	Gender	Mean (SD)	p-value	GMFCS	Mean (SD)	p-value
Q 1 Overall QoL	13-17 (28)	3.54 (1.17)	0.57 #	Male (29)	3.34 (0.86)	0.19 #	II (33)	3.30 (0.92)	<b>0.049 #</b>
	18-23 (23)	3.39 (0.84)		Female (22)	3.64 (1.22)		III (18)	3.78 (1.17)	
Q 2 General Health	13-17	3.32 (1.16)	0.95 #	Male	3.52 (0.99)	0.12 #	II	3.21 (0.96)	0.11 #
	18-23yr	3.39 (0.66)		Female	3.14 (0.89)		III	3.61 (0.92)	
Domain 1 Physical	13-17	51.4 (16.1)	<b>0.049</b>	Male	55.2 (15.8)	0.90	II	53.3 (13.2)	0.34
	18-23yr	59.3 (11.9)		Female	54.6 (13.7)		III	57.9 (17.3)	
Domain 2 Psychological	13-17	62.5 (20.0)	0.34	Male	59.6 (16.6)	0.76	II	55.0 (17.1)	<b>0.005</b>
	18-23yr	57.5 (16.4)		Female	61.2 (21.1)		III	69.9 (17.4)	
Domain 3 Social Relations	13-17	54.4 (20.0)	<b>0.049 #</b>	Male	55.0 (22.6)	<b>0.032 #</b>	II	40.3 (16.6)	<b>&lt;0.001 #</b>
	18-23yr	43.7 (22.8)		Female	42.6 (18.9)		III	66.7 (20.0)	
Domain 4 Environment	13-17	57.9 (21.8)	0.89	Male	55.3 (20.7)	0.21	II	54.8 (18.0)	0.08
	18-23yr	58.7 (14.8)		Female	62.1 (15.6)		III	64.5 (19.1)	

Bold: significant difference; #: statistics by Mann-Whitney test

Figure 1: Mean scores ( $\pm$  SD) of WHOQOL-BREF measurements in the three centers



## Discussion

### WHOQOL-BREF - general

We report the QoL of a sample of adolescents and young adults with CP from three communities in the Middle East, who were able to self-report. The study provides new information about the perceptions of adolescents and young adults with CP in Jordan, the PA, and Israel. For the entire group, the QoL scores were lowest in the social relationships domain and were highest in the psychological domain. These results coincide with those obtained in a study by Colver et al.,<sup>9</sup> which reported that the QoL of adolescents with CP is not lower than that of adolescents in the general population, apart from the domain of social support and peers. In our study, the social relations domain was significantly low for females, for the older group and for those of GMFCS II. Rosenbaum<sup>16</sup> emphasized the importance of helping parents and youths look beyond 'therapies' and the desire to 'fix' disabilities and instead to shift the paradigm towards finding the best ways to promote and develop the individual's capacity, performance, life satisfaction and independence. Similarly, Livingston and Rosenbaum suggest that QoL measures might be more useful than Health Related Quality of Life (HRQoL) for determining predictors of well-being or tracking changes over time, when assessing the impact of interventions designed to enhance life experiences of young people with disabilities.<sup>17</sup> Likewise, the general outcome of the current study's findings suggest that social life should be a major concern in rehabilitation.

### WHOQOL-BREF - Communities

The three location groups differed in general QoL, and in the psychological and environmental domains, which were the highest in Israel. The social relations domain was low for all centers and there was no significant difference between them. Saleh and Almasri have reported on the services available for children and adolescents ages 13-14 yrs with CP in Jordan.<sup>18</sup> During

the year previous to that report, participants received only one medical service and no community support. Also educational services were insufficient. The Israeli Special Education law ensures free special education services for individuals between 3 and 21 yrs of age. Integration into the mainstream education system is common and individuals with CP have the opportunity to volunteer for community or military service when they reach 18 yrs of age. Attending the education system is mandatory and includes systematic educational learning and treatments, including physiotherapy, speech therapy, occupational therapy and other treatments. Eight percent of all students in the special education system have CP. Recreation, sport and social activities are supported by the state and by nongovernmental organizations (NGOs).

The Palestinian Authority Central Bureau of Statistics survey found that many of the children with disabilities were not enrolled in public schools.<sup>19</sup> The Education Development Strategic Plan of the Palestinian Ministry of Education indicates that in 2014, 38% of individuals with disabilities of any kind did not have access to education at all, while 34% were enrolled in education, but had dropped out before completing the secondary level. In the Palestinian Authority - West Bank, the population with disabilities is diverse, as in other countries. Sixty percent of people with disabilities between the ages of 5 and 24 yrs were enrolled in a regular educational program. Here, the rehabilitation providers in institutions and in the community, as well as the social clubs and sport centers, are supported by NGOs. This is probably the main reason that five of the six categories of WHOQOL-BREF indicate the lowest average score for participants from the Palestinian Authority. The support system within the public services in both Israel and Jordan allows for better interaction with patients than that in the newly developed ministries of education, health and social welfare in the PA.

**WHOQOL-BREF - Age groups**

The comparison between the two age groups (13-17 yrs) and (18-23 yrs) in this study indicated no general health or overall QoL differences. However, the older group reported higher scores in the physical domain. Older participants are more stable in terms of physical challenges, which help them to perceive their physical QoL as better, compared to those at a younger age whose physical condition may be less stable. The participants in the younger group are still growing and developing and facing new challenges and changes in physical domains. The older group reported lower scores in the social domain, presumably, because the opportunities to socialize are fewer after leaving school or other educational or therapeutic support systems. For the younger group, social relationships are more about interacting with peers, whereas for the older group, the social aspect is related to issues such as sexual activity, life partners and intimate relationships. According to recent responses to the HRQoL index among healthy 10-19 yrs olds in Jordan, no significant age differences existed.<sup>20</sup> In the general population, the QoL of adolescents is reportedly lower than that of children, especially for girls. Also, new facets and domains of QoL emerge in adolescence, which point to an acceptance of disability, which is lower in childhood.<sup>21</sup> As children mature, particular aspects of QoL must be considered important for service delivery and health care interventions. Consequently, multiple considerations are required to best assess the QoL of these adolescents.<sup>22,23</sup> Skevington et al. suggested developing an adolescent version of the WHOQOL-BREF with cultural considerations.<sup>14</sup> We found, as in Skevington's study, that the question about sexual relations was the most problematic and also "work capacity" was not relevant to the younger group.

**WHOQOL-BREF - gender**

There were significant differences between males and females only in the social relations domain, where the females' scores were unusually low. In a UK study

for participants with diverse diseases and conditions, the QoL for all ages was "good" for both genders, with means from 61 to 68 on HRQoL.<sup>8</sup> No significant differences in the overall HRQoL index were found between healthy male and female student adolescents in Jordan, but male adolescents scored higher in physical and psychosocial well-being and autonomy.<sup>20</sup> The Jordanian and the Palestinian cultures are predominantly male societies, where boys are allowed to be outside the home for longer periods of time and free from the tighter restrictions placed on women and girls. Here most females require a family escort to go outdoors, with times restricted. The Israeli participants came from secular families.

**WHOQOL-BREF Mobility level (GMFCS)**

In the present study, participants with higher mobility level (GMFCS II) reported lower QoL in general, and in the psychological and social domains. In the other three categories, those with lesser mobility (GMFCS III) also had higher scores than those at level II, but differences were not significant. In a report by Helseth and Misvaer, adolescents' health was separated from their QoL:<sup>24</sup> health was related to their physical condition and QoL was related to their positive psychological experiences. According to the social model of disability,<sup>23</sup> the notion of social participation is about what a person does in daily life and is therefore strongly influenced by the environment. In this study, the report on environmental facets was not significantly higher for the GMFCS III group. In populations with disabilities, the QoL in general and the domains of physical well-being are more strongly associated with functioning than are the psychosocial domains.<sup>25</sup> Hence, a child with poor functioning may report good social and emotional well-being. Our results, although in adolescents, agree with that concept, showing overall QoL, psychological well-being and social relationships inversely related to motor-mobility level.

The "disability paradox" was described by Albrecht and Devlieger.<sup>26</sup> They found that over half of 153 adults with chronic disabilities, including CP, reported a high QoL, even with low income and social isolation. The explanation of the paradox has to do with establishing and maintaining a sense of balance between the body, mind and spirit and with the individual's social relationships and environment. A similar "caregiving paradox" was reported in a study of parents of children with CP by Carona et al.<sup>27</sup> Those parents reported a similar QoL as parents of children with no disabilities. These paradoxes highlight the importance of the adaptation potential of the parents and families. This paradox is clearly apparent in the current study.

## Conclusions and Interpretations

The adolescents and young adults with CP who live in the community and are affiliated with the three rehabilitations centers in the Middle East studied here did not differ significantly in their needs for maintaining and developing peer relationships from adolescents with CP in other regions, or from healthy individuals of the same age in other countries. The social relations domain was the lowest overall score of all domains, especially for females, the older group, and those with better mobility. The group at GMFCS II, closer in motor functioning to healthy peers, perceived themselves more socially isolated, perhaps because of higher expectations related to establishing and maintaining a "sense of balance between the body, mind and spirit."<sup>26</sup> These findings suggest that adolescents and young adults with CP need particular assistance in creating opportunities for their participation in recreational and social settings, in order to maintain and develop peer relationships. Special emphasis should be placed on empowering females in the traditional societies in the Middle East. Hence, participants' perceived QoL is an important factor that should be measured and taken into account when planning individual rehabilitation

programs or designing community services for people with disabilities.

## Limitations

Participants were recruited from small-ranging areas using a convenience sample, which limits the ability to generalize the findings to a cultural setting. In the social relations domain, the sexual activity question was problematic, as 50% of participants, predominantly females, did not answer this question, as was found also in a previous study.<sup>14</sup> The question regarding work capacity was not answered by seven participants and seems irrelevant for younger adolescents. The sample from Israel was smaller than those from Jordan and from the PA, leaving statistical comparisons between countries questionable.

## Acknowledgments

This research was supported by the United Cerebral Palsy Research Foundation (CPIRF).

We thank the staff and administration of the rehabilitation centers who assisted with this study.

## References

1. The WHOQOL Group. Development of the WHOQOL: rationale and current status. *Int J Ment Health*. 1994;23(3):24-56.
2. WHO Department of Mental Health. Annotated Bibliography of the WHO Quality of Life Assessment Instrument WHOQOL, October 1999 version, WHO/MNH/MHP/98.4.Rev.2.
3. WHO. Adolescent Health. Available from: [http://www.who.int/topics/adolescent\\_health/en/](http://www.who.int/topics/adolescent_health/en/).
4. WHO. Adolescence: a period needing special attention. Available from: <http://apps.who.int/adolescent/second-decade/section2/page1/recognizing-adolescence.html>.
5. Rosenbaum P, Paneth N, Leviton A, et al. A report: the definition and classification of cerebral palsy April 2006. *Dev Med Child Neurol Suppl*. 2007;109:8-14.
6. The WHOQOL Group. No authors listed. Development of the World Health Organization WHOQOL-BREF quality of life assessment. *Psychol Med*. 1998;28(3):551-558.
7. Skevington SM, Lofly M, O'Connell KA. WHOQOL Group. The World Health Organization's WHOQOL-BREF quality of life assessment: psychometric properties and results of the international field trial. A Report from the WHOQOL Group. *Qual Life Res*. 2004;13(2):299-310.
8. Skevington SM, McCrate FM. Expecting a good quality of life in health: assessing people with diverse diseases and conditions using the WHOQOL-BREF. *Health Expect*. 2012;15(1):49-62.
9. Colver A, Rapp M, Eisemann N, et al. Self-reported quality of life of adolescents with cerebral palsy: a cross-sectional and longitudinal analysis. *Lancet*. 2015;21:385 (9969):705-716.
10. NICE (National institute for health and care excellence UK) Newsletters and Alerts. Eyes on Evidence. Quality of life in young people with cerebral palsy, August 2015.
11. WHOQOL-BREF. Introduction, Administration, Scoring and Generic Version of the Assessment. Field Trial Version December 1996. Available from: [http://www.who.int/mental\\_health/media/en/76.pdf?ua=1](http://www.who.int/mental_health/media/en/76.pdf?ua=1)
12. Skevington SM, Sartorius N, Amir M. Developing methods for assessing quality of life in different cultural settings: the history of the WHOQOL instruments. *Soc Psychiatry Psychiatr Epidemiol*. 2004;39(1):1-8.
13. Skevington SM, Dehner S, Gillison FB, et al. How appropriate is the WHOQOL-BREF for assessing the quality of life of adolescents? *Psychol Health*. 2014;29(3):297-317.
14. Shikako-Thomas K, Lach L, Majnemer A, et al. Quality of life from the perspective of adolescents with cerebral palsy: "I just think I'm a normal kid, I just happen to have a disability". *Qual Life Res*. 2009;18(7):825-832.
15. Palisano R, Rosenbaum PL, Bartlett D, Livingston M. (2007). Gross motor function classification system expanded and revised. McMaster University, Ontario, Canada: CanChild Centre for Childhood Disability Research.
16. Rosenbaum PL. The quality of life for the young adult with neurodisability: overview and reprise. *Dev Med Child Neurol*. 2009;51(8):679-682.
17. Livingston MH, Rosenbaum PL. Adolescents with cerebral palsy: stability in measurement of quality of life and health-related quality of life over 1 year. *Dev Med Child Neurol*. 2008;50(9):696-701.
18. Saleh M, Almasri NA. Cerebral palsy in Jordan: demographics, medical characteristics, and access to services. *Child Health Care*. 2015;46(1): 49-65.
19. Hourani EM, Hammad SM, Shaheen A, Amre HM. Health-related Quality of Life among Jordanian adolescents. *Clin Nurs Res*. 2016;26(3):337-353
20. Palestinian Central Bureau of Statistics (PCBS). Available from: <http://www.pcbs.gov.ps/post.aspx?lang=en&ItemID=1271>
21. Colver A. Quality of life and participation. *Dev Med Child Neurol*. 2009; 51(8):656-659.
22. Shikako-Thomas K, Bogossian A, Lach LM, et al. Parents' perspectives on the quality of life of adolescents with cerebral palsy: trajectories, choices and hope. *Disabil Rehabil*. 2013;35(25):2113-2122.
23. Davis E, Shelly A, Waters E, et al. Quality of life of adolescents with cerebral palsy: perspectives of adolescents and parents. *Dev Med Child Neurol*. 2009;51(3):193-199.
24. Helseth S, Misvaer N. Adolescents' perceptions of quality of life: what it is and what matters. *J Clin Nurs*. 2010;19(9-10):1454-1461.
25. Shelly A, Davis E, Waters E, et al. The relationship between quality of life and functioning for children with cerebral palsy. *Dev Med Child Neurol*. 2008; 50(3):199-203.
26. Albrecht GL, Devlieger PJ. The disability paradox: high quality of life against all odds. *Soc Sci Med*. 1999;48(8): 977-988.
27. Carona C, Pereira M, Moreira H, et al. The disability paradox revisited: Quality of life and family caregiving in pediatric cerebral palsy. *J Child Fam Stud*. 2013;22(7):971-986.