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Quality of Life and Socioeconomic Status: A Comparative Study among Mothers of Children with and without Disabilities in Saudi Arabia

Reem Mohammed Alwhaibi^{a,b}, Uzma Zaidi^c, Ibtisam Alzeiby^d and Adel Alhusaini^e

^aRehabilitation Sciences Department, College of Health and Rehabilitation Sciences, Princess Nourah bint Abdulrahman University, Riyadh, Saudi Arabia; ^bDeanship of Scientific Research, Princess Nourah bint Abdulrahman University, Riyadh, Saudi Arabia; ^cHealth Sciences Department, College of Health and Rehabilitation Sciences, Princess Nourah bint Abdulrahman University, Riyadh, Saudi Arabia; ^dPsychology Department, College of Education, Princess Nourah bint Abdulrahman University, Riyadh, Saudi Arabia; ^eRehabilitation Sciences Department, College of Applied Medical Sciences, King Saud University, Riyadh, Saudi Arabia

ABSTRACT

A child's disability affects not only that child but also their caregivers. This study compares the quality of life (QoL) of Saudi mothers (primary caregivers) of children with Cerebral Palsy (CP) and Down Syndrome (DS) and mothers whose children do not have a disability, and explores its relationship with socioeconomic status. Two hundred mothers of children with disabilities and 99 mothers of children without disabilities were recruited from rehabilitation centers and regular schools, respectively. Information on their sociodemographic, social support, and QoL information was collected using the Quality of Life Index (QLI) – Generic Version III. The independent-samples t-test and Welch's test for QoL indicate that the mothers of children with disabilities have less satisfaction (QLI Part 1) in the social and economic subscale compared to the mothers of children without disabilities ($p=0.0068$) but no differences were found in the other domains. For QLI Part 2 (Importance), the mothers of children with disabilities were found to attribute more importance to health and functioning than mothers of children without disabilities ($p=0.003$). The former were also found to attribute less importance to their psychological/spiritual status than the latter ($p<0.01$). There was no significant difference in total score or in the family or socioeconomic domains. It is concluded that Saudi mothers of children with disabilities need more social support and professional help to improve their quality of life.

KEYWORDS

Quality of life; socioeconomic status; Saudi Arabia; children with disabilities; parents of children with disabilities

Introduction

Quality of Life (QoL) is a significant aspect of health. It has been defined by the World Health Organization (WHO) 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,

CONTACT R. M. Alwhaibi  rmalwhaibi@pnu.edu.sa  Rehabilitation Sciences Department, College of Health and Rehabilitation Sciences, Princess Nourah bint Abdulrahman University, P.O. Box 25058, Riyadh 11466, Saudi Arabia; Deanship of Scientific Research, Princess Nourah bint Abdulrahman University, P.O. Box 25058, Riyadh 11466, Saudi Arabia

expectations, standards and concerns” (WHOQOL Group, 1995). Within the scope of QoL, the WHO considers physical health, psychological state, degree of independence, social relationships, personal views and beliefs, alongside important characteristics of the environment, such as physical safety and security, and the accessibility and quality of health and social care. Disability has many consequences at the personal, interpersonal, family, and social levels, as it affects level of independence, physical health, psychological state, family life, and social relationships (Barbotte, Guillemin, & Chau, 2001).

Cerebral palsy (CP) and Down syndrome (DS) are neurological conditions that have specific characteristics in common (Brown & Percy, 2009). The prevalence of CP is 2–3 cases per 1,000 live births worldwide (Odding, Roebroek, & Stam, 2006), while that of DS is between 1 in 1,000 and 1 in 1,100 live births (WHO, 2014). CP is characterized by gait and posture impairment affecting muscle coordination and bodily movement (Odding et al., 2006). Many children with CP also suffer from intellectual, sensory, and/or speech impairment; perception and behavioral disorders (Manuel, Naughton, Balkrishnan, Paterson Smith, & Koman, 2003; Odding et al., 2006; Raina et al., 2005); and epilepsy (Odding et al., 2006). DS is characterized by varying degrees of poor motor control, intellectual disability, behavioral problems, and/or speech, hearing, and vision impairments (Dumas, Wolf, Fisman, & Culligan, 1991; Sanders & Morgan, 1997); people with DS are also at increased risk for a number of comorbid conditions, such as cardiac, gastrointestinal, musculoskeletal or orthopedic, and endocrine conditions, as well as epilepsy (Dumas et al., 1991; Sanders & Morgan, 1997).

A parent’s coping pattern to learning their child has a disability varies from reactions of mourning and crisis to acceptance (Hatton, Akram, Robertson, Shah, & Emerson, 2003; Kandel & Merrick, 2005; Kandel, Morad, Vardi, & Merrick, 2005). However, very often the reaction to the birth of such a child starts with shock, followed by denial and rejection of the child’s diagnosis; there might also be some feelings of disappointment, guilt, grief, sorrow, helplessness, and fear of the degree of disability and the unknown future (Ellis & Hirsch, 2000; George, Vickers, Wilkes, & Barton, 2007; Graungaard & Skov, 2007; Ho & Keiley, 2003; Huang, Kellett, & St John, 2010). Although caring for a child with a disability negatively affects the physical and psychological health, marital and social relationships, and employment and financial status of both parents (Davis et al., 2010), mothers are reported to be more affected (Bumin, Günal, & Tükel, 2008; Glidden & Jobe, 2006; Smith, Innocenti, Boyce, & Smith, 1993). They often experience greater feelings of guilt and responsibility for the child’s disability than do other family members (Götz & Götz, 2000; Smith et al., 1993), thus both psychological and physical health of mothers may be harmed as a result of the demanding work they face daily (Abbeduto et al., 2014; Al-Eithan, Al Juban, & Robert, 2013; Diwan, Chovatiya, & Diwan, 2011; Davis et al., 2010; Escobar et al., 2005; Kavlak, Altuğ, Büker, & Şenol, 2015; Kaya et al., 2010; Khayatzadeh, Rostami, Amirsalari, & Karimloo, 2013; Lin et al., 2009; Ones, Yilmaz, Cetinkaya, & Caglar, 2005; Prudente, Barbosa, & Porto, 2010; Raina et al., 2005; Seltzer, Greenberg, Floyd, & Hong, 2004; Singer, 2006; Tal-hatu & Mordi, 2007; Tekinarslan, 2013).

A major reported reason for this stress is that many mothers spend most of their daily time with their children (Bilgin & Gozum, 2009; Ganong, Doty, & Gayer, 2003). Stress and the development of stress-related problems emerge from the demands of caregiving, earning a living, and other responsibilities (Ganong et al., 2003). Conversely, mothers’ psychological well-being has been found to be associated with levels of formal support

from professionals and informal support from their spouse, family, and friends; this includes a wide array of advice, emotional support, and assistance with everyday tasks (White & Hastings, 2004).

As the primary caregivers, Saudi mothers of children with disabilities face several challenges that directly affect their own physical health and psychological wellbeing (Al-Eithan et al., 2013; Bakhsh, 1990; Sijeeni, 2016). Since the culture, traditions, and customs of Saudi Arabia are unique, they need to be briefly introduced, principally with regard to mothers of children with disabilities and the services provided to their children.

Saudi society

Saudi Arabian society is generally founded upon Islamic religious instruction, characterized by conservative, traditional, and family oriented values. Parents take care of their children until they are married or can financially support themselves. When parents grow old, their children take care of them. Customarily, men hold more power than women in the home with regard to making decisions and taking actions (Bakadir, 1998; Khatib, 1997). Grandparents are highly respected and play a prominent role in decision making on many family issues, especially if they live with their children and grandchildren. Furthermore, women are not expected to work outside the home, which is reflected in the proportion of Saudi women in the labor force (about 9.7%) (General Authority for Statistics (GAS), 2016a). In addition, they have only very recently been permitted to drive and, consequently, have limited mobility (Khatib, 1997). According to national customs, women are in charge of all the housework and raising children (Sijeeni, 2016).

Disability and societal reactions

Based on a recent report by Saudi Arabia's General Authority for Statistics (GAS), the prevalence rate of disability among the Saudi population is 33 per 1,000 (GAS, 2016b). The DS prevalence rate is 1.8 per 1,000 live births, which is higher than the respective rates in neighboring countries (Amir, Al-Tawila, & Al-Harbi, 2002). The CP prevalence rate is 2.34 per 1,000 live births (Al Salloum, El Mouzan, Al Omar, Al Herbish, & Qurashi, 2011]. The typical reaction of Saudi parents to the diagnosis of disability in their child is similar to that reported in other cultures (George et al., 2007; Graungaard & Skov, 2007). However, in Saudi Arabia, personal and family pride plays a significant role in shaping both individual and family behavior within society. For instance, some close family members feel embarrassed and ashamed by a child with a disability, feeling the disability conveys a defect in the child's parents (Sijeeni, 2016). Furthermore, some family members tend to prevent their typically developing child from playing with those born with a disability; even their facial expressions indirectly indicate negative feelings toward children with disabilities. Such behaviors are more likely to occur in rural, rather than urban, areas, and lead to social withdrawal (Deeb, 2005; Sijeeni, 2016).

Services provided to children with disabilities

The Saudi Government, through the Ministry of Labor and Social Development (MLSD), provides many types of support to parents of children with disabilities. For instance, there

are many governmental and private centers designed specifically for children with disabilities. These centers are located in major cities like Riyadh, Dammam, and Jeddah. However, the number of rehabilitation centers around the country does not fully cover the needs of the population. For example, in Jeddah, of a total of about 150,000 children with disabilities, only 7,000 are beneficiaries of training and rehabilitation centers. In comparison with Jeddah, there are about 156,110 children with disabilities in Riyadh with the number of children benefiting from the training and rehabilitation centers around 22,356 only (MLSD, 2015). Most of these centers are privately operated, with fees starting from US\$6,700 and rising in accordance with the severity of the child's condition and the services provided. The MLSD is currently opening new comprehensive rehabilitation centers for children with disabilities, expanding existing ones, working on developing them, and supporting them with qualified staff (MLSD, 2015). The financial support given by the government to each family of a child with a disability ranges from US\$2,560–3,730 per year, based on the degree of disability (MLSD, 2015; Sijeeni, 2016). Although this amount is insufficient to cover the fees of many services provided to these children, especially if they attend a private center, it is a meaningful supplement (ILO, 2011). The MLSD is currently formulating an increase in the government funding to these families, aiming to set the amount in proportion to the requirements of each disability and the family's standard of living. The objective is to encourage families to care for children with disabilities in their homes or to enroll them in specialized centers. It will also be necessary to implement controls to ensure that children with disabilities benefit from this funding (MLSD, 2015).

Early intervention programs are only provided by some private centers. These programs are very limited, fairly costly (ranging from US\$4000 to \$7000 per year), and accept children from birth to three years old. They comprise monthly educational sessions for parents, specialized consultancy sessions, tailored training programs, and, on some occasions, home visits (Deeb, 2005; Sijeeni, 2016). However, these programs are not followed by similar services for older children. The MLSD is working to increase the availability of community-based rehabilitation, such as daycare programs and homecare programs (MLSD, 2015).

Long-term caregiving for children with chronic conditions such as CP and DS can be detrimental to the mother's QoL. Several studies have proposed mediating factors in this regard, which can be grouped into the following: child characteristics, such as age, sex, type of disability, and behavior (Dempsey, Keen, Pennell, O'Reilly, & Neilands, 2009; Kabasakal, Girli, Totan, & Aysan, 2012); caregiver characteristics, such as age, marital status, education level, and coping strategies (Badaru, Ogwumike, Adeniyi, & Kaka, 2013; Kabasakal et al., 2012); family characteristics, such as how well the family functions and their financial resources (Parish, Seltzer, Greenberg, & Floyd, 2004; Paster, Brandwein, & Walsh, 2009); and sociological characteristics, such as social support and employment (Badaru et al., 2013; Dempsey et al., 2009; Khayatzadeh et al., 2013; White & Hastings, 2004). Some or all of these factors may directly affect QoL for of the mothers of children with disabilities (Tekinarslan, 2013; Wiley & Renk, 2007).

The present study aims to yield information on the situation of mothers of children with disabilities, focusing specifically on CP and DS, in the unique Saudi cultural context. Our hypothesis was to determine if the data from mothers of children with disability were significantly different from data obtained from mothers of children without disabilities. To do so, the study compares the QoL of Saudi mothers of children with

disabilities (CP and DS) with that of mothers of children without disabilities, and explores its relationship with socioeconomic status.

Materials and methods

Participants

The participants of the study were 299 mothers (155 mothers of children with CP and 145 mothers of children with DS), residing in Riyadh which is the capital and the most populous city in Saudi Arabia (Central Department of Statistics & Information, 2016). The mothers were recruited through purposive sampling from two governmental rehabilitation centers for females and a private daycare center. The inclusion criteria for this group were: first (a) their child has been diagnosed with CP or DS; also (b) their child's age ranges from two to ten years. The exclusion criteria was any acute physical or psychological health changes in the past two weeks.

The control group comprised 100 mothers of children without disabilities. Mothers were recruited from one public elementary school, one private daycare school, and one public daycare center in Riyadh. The inclusion criteria for this group were as follows: (a) their child is aged between two and ten years; and (b) their child is typically developing; has no mental, developmental, or physical disability; and is not receiving ongoing prescription medication. The exclusion criteria were the same as for the study group; one mother was excluded, leaving 99 in the control group.

Characteristic of respondents

The ages of the study participants ranged from 21 to 63 years. The mean age was 40.2 (± 7.59). The mean age of mothers of children without disabilities was 37.01 ± 8.56 and that of mothers of children with disabilities was 41.54 ± 7.06 . The main socioeconomic statuses of the participants are given in [Table 2](#).

Procedures

The first part of the study was conducted with the mothers of children without disabilities, from July to August 2016. The second part was then conducted with the mothers of children with disabilities from September to December 2016. All of the institutions, schools and the Rehabilitation centers, attended by children of the participants, were under the umbrella of the MLSD. In addition to restricted data collection time, the long administrative procedures of some schools and rehabilitation centers impacted on the recruitment of participants.

Instruments

This is a cross-sectional study using a post-positivist research paradigm reflecting a deterministic philosophy (Creswell, 2003; MLSD, 2015). As the study's participants could not spare much time, it was not feasible to collect qualitative data. The research method applied was quantitative in nature: a survey using a standardized instrument to establish each child's degree of disability using Gross Motor Function Classification System

(GMFCS) and self-report questionnaire to assess the perceptions of mothers using Quality of Life Index (QLI) – Generic Version III. All the participants received detailed written and verbal information about the study and brief instructions on how to respond to the questionnaire; then, the demographic information of the participants was recoded using Socio-demographic information form.

Gross motor function classification system (GMFCS)

It has been reported that a child's level of disability can increase the caregiving burden and affect caregivers' QoL (Dambi, Jelsma, & Mlambo, 2015; Piran, Khademi, Tayari, & Mansouri, 2017). Therefore, the Gross Motor Function Classification System (GMFCS) was used. It is often employed to assess motor function in the lower limbs of children with CP, with particular emphasis on sitting, walking, and wheeled mobility. The GMFCS is widely used in clinical examinations, research, and population-based studies, and has been internationally validated in relation to ambulation and activity limitations (Hanna et al., 2009; Palisano et al., 1997; Palisano, Cameron, Rosenbaum, Walter, & Russell, 2006; Pfeifer, Silva, Funayama, & Santos, 2009; Rosenbaum, Palisano, Bartlett, Galuppi, & Russell, 2008). It is a five level age-categorized system that is developed to classify the severity of motor involvement in children with CP, based on functional abilities and limitations. Children classified as Level I are independent walkers without the use of assistive mobility devices in all settings whereas children at Level V have severe limitations in head and trunk control and consequently need wheeled mobility.

Sociodemographic information form

A personal information questionnaire, prepared by the researchers, was used to gather sociodemographic information. It was divided into four parts. The first part covered information related to the child such as age, gender, birth order, and (if relevant) type of disability (CP or DS) and any associated symptoms. The second part covered information related to the mother, such as age, education level, employment status and work history, family monthly income, marital status, and any health problems. The third part covered information about the family, such as total number of family members, family structure, number of children, and type of housing. The final part covered information about existing support for the mother within the family.

Quality of life index (QLI) – generic version III

This tool was developed by Ferrans and Powers between 1984 and 1998. Several versions have been developed to be used with the general population and in relation to various disorders. The questionnaire contains 33 items and yields scores for five categories, total quality of life, health and functioning, social and economic, psychological and spiritual, and family. All questions were answered on a five-point Likert-type scale (1 = very unsatisfied, 5 = very satisfied); higher scores indicate greater satisfaction in a given area resulting in better quality of life. The internal consistency reliability of the QLI is supported by several studies ($\alpha = 0.73$ to 0.99; Ferrans, 1990); this measure also has high construct and convergent validity (Kimura & Silva, 2009). The 2006 Arabic translated version by Halabi, which has high reliability, was used.

Ethical considerations

The study was approved by the appropriate Ethics Committee. The consent form was given to the potential participants with the description of the procedures and the purpose of the study in detail. Two female researchers administered a brief structured interview to screen participants according to the research criteria and gathered their demographic information. Due to the limited time frame available for data collection, after rapport-building, instruments were administered to participants who were assured of the confidentiality of their information.

Statistical analysis

The Statistical Package for Social Sciences (SPSS) version 22.0 of Windows was used to analyze the collected data. Descriptive statistics were reported for sociodemographic characteristics. The results of continuous variables were expressed in terms of means and standard deviations while categorical variables were expressed as proportions and frequencies. Five scores were calculated on the QLI: the total quality of life score, health and functioning subscale score, social and economic subscale score, psychological and spiritual subscale score, finally family subscale score. The QLI comprises both Satisfaction (Part 1) and Importance (Part 2). For QoL, a t-test was used to assess the null hypothesis, determining if the two sets of data were significantly different from each other. The t-test assumed equal variances from which the two sets of data were sampled from populations with identical standard deviations and, thus, identical variances, even if their means were distinct. When a sample size and variances were unequal between the two groups, Welch's test for unequal variances which is also called Welch's t-test, Welch's adjusted t, or the unequal variances t-test was used, as it performs better than the Student's t-test in this situation. For socioeconomic status (SES), a chi-squared test was used to compare the two groups on categorical variables, followed by a chi-squared test for trend.

Results

Quality of life

Table 1 shows the mean scores for total quality of life and its domains. The results of the independent-samples t-test and Welch's test for Part 1 (Satisfaction) indicated no significant difference between the two groups in total score or in the health/functioning, family, and psychological/spiritual domains. However, there was a significant difference between them in the social/economic domain ($p = 0.0068$). The independent-samples t-test and Welch test for Part 2 (Importance) indicated no significant difference in total score or in the family and social/economic domains, but significant differences were found in the health/functioning ($p = 0.003$) and psychological/spiritual ($p < 0.01$) domains.

Socioeconomic status (SES)

The results for socioeconomic information show to some extent that mothers of children with disabilities are likely to have fewer resources than mothers of children without

Table 1. The five subscales of the Quality of Life Index: total scale score, health and functioning subscale, social and economic subscale, psychological and spiritual, and family subscale.

QLI	Domain	Mothers of children without disabilities (n = 99)			Mothers of children with disabilities (n = 200)			Effect size (Cohen's d)	Independent samples t-test(p)	Welch test (p)
		Mean	SD	95% CI	Mean	SD	95% CI			
Part 1 (Satisfaction)	QLI score (total)	22.273	3.6584	21.543–23.002	22.350	3.5919	21.849–22.851	0.02	0.8620	–
	Health/functioning (13 items)	21.768	3.9945	20.971–22.564	22.005	3.7316	21.485–22.525	0.06	0.6136	–
	Family (5 items)	23.333	4.4332	22.449–24.218	24.385	4.6199	23.741–25.029	0.23	0.0615	–
	Social/economic (8 items)	21.717	3.8440	20.950–22.484	20.350	4.1899	19.766–20.934	0.34	<0.01	–
	Psychological/spiritual (7 items)	23.242	4.2954	22.386–24.099	24.060	3.3932	23.587–24.533	0.21	–	0.0998
Part 2 (Importance)	QLI score (total)	27.545	1.9963	27.147–27.944	27.445	2.0611	27.158–27.732	0.05	0.6889	–
	Health/functioning (13 items)	27.606	2.2307	27.161–28.051	28.385	1.8340	28.129–28.641	0.38	–	<0.01
	Family (5 items)	28.394	2.0791	27.979–28.809	28.030	2.1170	27.735–28.325	0.17	0.1604	–
	Social/economic (8 items)	25.475	3.2868	24.819–26.130	25.365	3.2657	24.910–25.820	0.03	0.7851	–
	Psychological/spiritual (7 items)	29.081	1.8827	28.705–29.456	27.775	2.3606	27.446–28.104	0.6	–	<0.01

disabilities (in terms of an education, job, owning accommodation, and number of people sharing their accommodation). Table 2 shows that both groups' members are mostly married, as opposed to divorced or widowed: 87 (87.9%) and 173 (86.5%) for mothers of children with disabilities and mothers of children without disabilities, respectively. However, the chi-squared test shows no association between group and marital status (that is, the proportion is the same for mothers with children with disabilities and for mothers of children without disabilities). Regarding educational status, the majority (67) of mothers of children without disabilities have a bachelor's degree (67.7%), while 128 (74%) of mothers of children with disabilities their educational attainment was at high school level. A chi-squared test shows a significant association between group and education (that is, the proportion differs between mothers of children with disabilities and mothers of children without disabilities). Regarding job status, 63 (66.3%) of mothers of children without disabilities are employed and 32 (16%) of mothers of children with disabilities are employed. A chi-squared test shows that this difference is significant. Accordingly, most mothers of children with disabilities (57%) were found to have average family monthly income of SAR5,000–10,000 (US\$1,333.24–2,666.49), Meanwhile, most mothers of children without disabilities (51.5%) were found to have average family monthly income, less than SAR5,000 (US\$1,333.24), with 10% in the highest category of SAR15,000 per month (equivalent to US\$3,999.70) or more. As regards to housing or accommodation status, most mothers of children with disabilities were living in rental apartments 113 (56.5%) inhabited by around 6–9 people (74%), while mothers of children without disabilities were living in houses owned by them or their husband 52 (52.5%), shared with around 4–6 people (57%). The associations between group and economic status and between group and number of people sharing the accommodation were significant ($p < 0.01$) and ($p < 0.01$) respectively.

Discussion

Disability is a complex, multidimensional phenomenon relevant to wide-ranging disciplines, including healthcare, medicine, psychology, sociology, economics, and policy (Al-Gain & Al-Abdulwahab, 2002). Disabilities impact not only the people who have them but also their families (Davis et al., 2010). In previous studies, families, and especially mothers, of children with disabilities have been found to suffer from anxiety, depression, and low QoL (Al-Eithan, Robert, & Al-Saeed, 2010; Bumin et al., 2008; Glidden & Jobe, 2006; Kazmi, Perveen, Karamat, & Khan, 2014). The burden of psychological illness directly impacts the well-being of not only the afflicted individual but also those around them and, ultimately, society as a whole. Aside from QoL, socioeconomic status also plays a vital role in helping mothers and other caregivers for people with disabilities to face the challenges of life (Neely-Barnes & Dia, 2008; Parish et al., 2004).

QoL related to disabilities and their impact on parents has been an area of special interest for experts in growth and development. Most prior research on QoL for parents of children with disabilities has performed comparisons across different disabilities (Haimour & Abu-Hawwash, 2012). Limited literature was found comparing QoL for caregivers of children with and without disabilities (Malhotra, Khan, & Bhatia, 2012). This is partly because prior studies used QoL measures other than QLI – Generic Version III (Ahmadizadeh,

Table 2. Chi-squared results for socioeconomic status.

Variable	Codes						Chi-Squared Test (p)	Chi-Squared Test for Trend (p)	
Marital Status	1 (Married)	2 (Separated)	3 (Widowed)	Total			0.5606	0.5147	
Mothers of children without disabilities	87	11	1	99 (33.1%)					
Mothers of children with disabilities	173	21	6	200 (66.9%)					
Total	260 (87.0%)	32 (10.7%)	7 (2.3%)	299					
Level of Education	1 (Graduate)	2 (Undergraduate)	3 (Secondary)	4 (Elementary)	Total		<0.01	<0.01	
Mothers of children without disabilities	18	67	10	4	99 (33.1%)				
Mothers of children with disabilities	1	51	128	20	200 (66.9%)				
Total	19 (6.4%)	118 (39.5%)	138 (46.2%)	24 (8.0%)	299				
Job Status	1 (Employed)	2 (Housewife)	3 (Unemployed)	4 (Self-Employed)	Total		<0.01	<0.01	
Mothers of children without disabilities	63	18	13	5	99 (33.1%)				
Mothers of children with disabilities	32	4	130	34	200 (66.9%)				
Total	95 (31.8%)	22 (7.4%)	143 (47.8%)	39 (13.0%)	299				
Income	1 (1500–3000 SR)	2(3000–5000 SR)	3(5000–10000 SR)	4(10000–15000 SR)	5(more than 15000SR)	Total	<0.01	<0.01	
Mothers of children without disabilities	33	17	31	6	10	97 (32.47%)			
Mothers of children with disabilities	4	39	114	36	7	200 (67.3%)			
Total	37 (12.4%)	56 (18.9%)	145 (49.0%)	42 (14.2%)	17 (5.7%)	297			
Type of Accommodation	1 (With Husband's Family)	2 (Apartment Rental)	3 (Own Apartment)	4 (House Rental)	5 (Own House)	6 (With Wife's Family)	Total	<0.01	<0.01
Mothers of children without disabilities	6	18	3	17	52	3	99 (33.1%)		
Mothers of children with disabilities	13	113	1	36	14	23	200 (66.9%)		
Total	19 (6.4%)	131 (43.8%)	4 (1.3%)	53 (17.7%)	66 (22.1%)	26 (8.7%)	299		

SR = Saudi Riyal.

Rassafiani, Khalili, & Mirmohammadkhani, 2015), and partly because studies using QLI have not calculated the total QoL score, focusing instead on the dimensions of QoL. The latter studies, thus, provide good sources of data for the QLI subscales but not for overall QoL (Malhotra et al., 2012). One study, employing a correlational design, reported that parents and caregivers of CP children and adolescents considered their own QoL to be good (Oliveira & Limongi, 2011). Although this study found no statistically significant difference in overall QoL, the mean variations do indicate an interesting difference. Mothers of children without disabilities scored a higher mean on the importance of QoL. While this study's overall QoL finding is confirming to that of previous studies, this difference in mean can be explained by prior findings that mothers of children with disabilities usually exhibit more dissatisfaction about their QoL due to their excessive responsibilities (Al-Eithan et al., 2010); they also give less importance to QoL and well-being, which may put them at risk for depression (Singer, 2006).

In this study, QoL was divided into four dimensions. Health and functioning are considered to be essential to learning, development, adaptation and adjusting to one's environment (Ferrans & Powers, 1985). Here, it is worth mentioning that no difference was found between the two groups on satisfaction with health and functioning QoL domain, but mothers of children with disabilities were found to assign more importance to health and functioning compared to mothers of children without disabilities. Children with disabilities frequently do not achieve normal developmental milestones and continuously need support, guidance, training and management to access the available interventions in order to express their full potential (Irwin, Siddiqi, & Hertzman, 2007). Thus, mothers of children with disability have to put more effort into raising these children and were found aware of importance of their own health and functioning, upon which the care of their children depends. It has been reported in previous studies that mothers of children with disability to be more likely to neglect their own health, functioning, and QoL (Al-Eithan et al., 2010). In this study mothers of children with disability give importance to health and functioning, but were found not satisfied. Previous studies utilizing the QLI have mentioned various factors affecting health and functioning, such as attitude toward consulting the health care system, pain, fatigue, autonomous self-care, longevity, and ability to take care of the family (Ferrans & Powers, 1985). This discrepancy between satisfaction and importance can be explained by referring to various theories (theory of reasoned action; health belief model) and assessment tools (e.g. the knowledge, attitude, and practice (KAP) survey) frequently used by health professionals (Glanz, Rimer, & Viswanath, 2008). As people do not necessarily implement their knowledge in practice, it is feasible that mothers of children with disabilities recognize the importance of their health and yet fail to act accordingly.

The family dimension of QoL includes family health, children, family happiness, spouse, and emotional support from the family (Michalos, 2014). No significant difference was found between the two groups on this variable. It is important that both group's means are much higher than half of the maximum possible score (30). Mothers of children with and without disabilities scored high on both satisfaction (Mean = 24.38 and 23.33, respectively) and importance (Mean = 28.03 and 28.39, respectively). This can be explained by the due respect and importance given to families in Saudi Arabia's collectivist culture. Moreover, the high average scores for satisfaction with this QoL dimension

reinforce the medium level of life satisfaction found among parents of autistic children in Saudi Arabia (Asi, 2016). With regard to marital status, the findings were almost identical for the two groups: 87% of mothers of children without disabilities were married, compared to 88% of mothers of children with disabilities. It has been found that family bonding and functioning may be disturbed by extra care being provided to children with disabilities, which may cause relational problems between spouses (Haimour & Abu-Hawwash, 2012; Kazmi et al., 2014). However, in collectivistic societies, family responsibilities and family ties are valued in the community, explaining the high proportion of married parents, regardless of their children's disability status. On the other hand, disapproval of social norms of society can also contribute to the high proportion of married parents. A prior study conducted in Riyadh supported the importance of family relationships in this context by showing average familial and social QoL domains for parents of children with disabilities (Asi, 2016).

Regarding the social and economic dimensions of QoL, there were no significant differences between the mothers of children with and without disability on satisfaction level. In terms of mean scores, mothers of children without disabilities showed greater satisfaction ($M = 21.71$) with their socioeconomic status than mothers of children with disabilities ($M = 20.35$). Usually, Saudi parents of children with disabilities suffer the costs of additional health care and facilities, increasing their financial burden and leaving them dissatisfied (Al-Jadid, 2013; MLSD, 2015). This might be due to their excessive responsibilities in simultaneously performing different roles (a mother, a wife and a daughter-in-law) and related to the needs of their child with a disability. These findings are supported by previous researches in terms of social (Khayatzadeh et al., 2013; Sijeeni, 2016) and economic (Parish et al., 2004) dissatisfaction of parents of children with disability. Furthermore, this finding from QoL measure has been reinforced by the socioeconomic status analysis (Table 2). Mothers of children with disability had less education, were unemployed and living in rental accommodation. Beside the factor of disability of child above mentioned socio-economic factors boost dissatisfaction toward QoL (Khayatzadeh et al., 2013; Sijeeni, 2016).

The final dimension of QoL is psychological/spiritual. It includes peace of mind, faith, attainment of personal goals, and so on. No difference was found in satisfaction with the psychological/spiritual dimension between the mother of children with or without disability. However, mothers of children without disabilities assigned more importance to spiritual and psychological QoL. Previous literature provides the support toward negligence of psychological wellbeing of mothers of children with disability (Al-Eithan et al., 2013; Sijeeni, 2016).

It is noteworthy that mothers of children with disability were found to have lower socioeconomic status (NCES, 2008) as compared to the control group. Saudi women account for 9.7% of the labor force (General Authority for Statistics (GAS), 2016a) but in the current study, 31.8% (95 out of 299) of mothers of children with or without disability were employed. It shows high numbers of employment were found in the current sample. This could be due to the geographical location of Riyadh. The city is thickly populated, an educational and cultural hub, and is rapidly becoming a metropolitan city (Saudi vision, 2030, 2016). Masses are moving to Riyadh for Medical, Engineering and other educational fields.

Conclusion and recommendations

The present study concludes that in terms of satisfaction, no statistically significant difference was found on social and economic dimensions of QoL between Saudi mothers of children with and without disabilities. Mothers of children with disability were found dissatisfied for their economic and social domains of QoL. Thus, mothers of children with disabilities need more social support and professional help to improve their general QoL. In terms of importance, mothers of children with disability had given more weight to health and functioning. Coping strategies and cognitive restructuring can be utilized to enhance optimistic attitudes and problem-focused approaches among mothers, ultimately, leading to improvement in their psychological QoL and wellbeing (Gupta & Singhal, 2004). Whereas, mothers of children without disability gave more importance to psychological and spiritual domains of life. Further, psychoeducation on behavioral issues and guidance on disease prevention measures would also be helpful for taking care of these children. For instance, health education workshops can be conducted to prepare mothers for potential risks or help them to identify symptoms of health hazards, enabling them to plan better health functioning for them and their children. While there are existing Saudi government programs to support children with disabilities, these efforts should be enhanced to support and meet the needs of their mothers and other family members, as well as of the children themselves.

A future qualitative study may glean more detailed information on this topic, reinforcing this study's call for improving support for mothers of children with disabilities. To get first-hand knowledge about the needs and capacity of Rehabilitation centers, a brief survey can be conducted with the staff members. On the basis of survey outcomes various strategies could be formulated to support the families and mothers of children with disabilities. This could provide a strong platform for them to share their experiences and reduce emotional stress. In future research, various psychological factors – for instance, anxiety, depression, and stress – can be explored as potential mediators of QoL. Moreover, mothers' quality of life can be compared across severity levels of their children's disabilities. In future research, other family members can be considered as caregivers alongside parents to measure and understand the familial support, care, and needs related to children with disabilities. A brief survey of the staff at the institutions could be helpful to understand the social support factor. Furthermore, a focus group of a sample of women may help to explore and reveal more in-depth information, further developing psychoeducational programs for family members. The sample can be increased to measure the validity and reliability of the variables in future. Furthermore, studies investigating the strength of association between the current study variables and the outcomes are recommended. Given the limited prior research investigating the QoL of mothers of children with CP and DS, it is hoped that this study will prompt action from the relevant Saudi Authorities to support the physical health and psychological wellbeing of such mothers and, thus, their children, for whom they are the main caregivers.

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No potential conflict of interest was reported by the authors.

Ethical considerations

The study was approved by the Deanship of Scientific Research Council and the Research Ethics Committee of the Health and Rehabilitation Sciences College at Princess Nourah bint Abdulrahman University, in Riyadh, by the Saudi Ministry of Labour and Social Development (required as data were collected from the Comprehensive Rehabilitation Centers and daycare center), and by the Saudi Ministry of Education.

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Geolocation

Saudi Arabia

Notes on contributors

Reem Mohammed Alwhaibi Associate professor of pediatric physical therapy. Dean of preparatory year and supervisor of foundation year of health colleges. Got a Bachelor's degree in Physical Therapy from King Saud University, Riyadh, Saudi Arabia, Master's degree in Rehabilitation from Pittsburgh University, and PhD in Pediatric physical therapy from Newcastle-upon-tyne in 2019. Professor Reem has held many administrative and academic positions, translated 3 books, co-author 1 book and has 10 published articles.

Dr. Uzma Zaidi, PhD in Clinical Psychology. Currently working as Associate Professor/Program Director of Clinical Psychology at Princess Nourah bint Abdulrahman University. Having experience of 12 years teaching and 11 years of Clinical Practice. Author of more than 20 research articles related to Clinical Psychology, Health Psychology, Personality Psychology, Neuropsychology, Educational Psychology and Organizational Behavior

Ibtisam Abdullah Alzeiby is an assistant professor in Psychology Department, College of Education, Princess Norah bint Abdulrahman, Riyadh, KSA. She has obtained her Bachelor's degree in Chemistry from College of Education, Madinah, KSA (1999). Also, she has obtained her Master's degree in Health Psychology (2004) and PhD in Psychology, from the Department of Psychology, PNU, Riyadh, KSA (2010). Previous Chairman of Psychology department at PNU, previous Director of Psychology program at PNU as well.

Adel Abdullah Alhusaini is an assistant professor in Rehabilitation Department, College of Applied Medical Sciences at King Saud University, Riyadh, KSA. He has obtained his master's degree in in Physiotherapy from Cardiff University, Cardiff, UK (2005). Also, he has obtained PhD in Pediatric Neurorehabilitation from School of Physiotherapy, Faculty of Health Sciences, University of Sydney, Sydney, NSW, Australia (2010). He has published More than 20 peer-reviewed publications

and one book published. He is also the chairman of Pediatric Neurorehabilitation Research group at KSU. Presently working on the KACST project regarding sedentary behavior characteristics and physical activity levels in children of Saudi Arabia

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