ORIGINAL ARTICLE

Investigation of Quality of Life Determinants Among Mothers of Children with Pervasive Developmental Disorders in Iran

Mohammad Khayatzadeh Mahani*, Hamid Reza Rostami, Seyfollah Jahantabi Nejad

Musculoskeletal Rehabilitation Research Center, Occupational Therapy Department, School of Rehabilitation, Ahvaz Jundishapur University of Medical Sciences, Ahvaz, Iran

Received 8 September 2012; received in revised form 23 March 2013; accepted 26 March 2013

KEYWORDS
marital satisfaction; mothers; pervasive developmental disorders; quality of life; socio-economic status; subtypes

Summary
Objective/Background: The objective of the study was to examine the association between socio-economic status (SES), marital satisfaction, and subtypes of pervasive developmental disorders (PDDs) with quality of life (QOL) in mothers of children with PDDs.

Methods: The study was conducted using a convenience sample of 210 mothers of children with PDDs. Data were collected using the World Health Organization QOL-BREF, Index of Marital Satisfaction, and SES Questionnaires. Data analysis was done by analysis of variance and multivariate analysis of variance tests.

Results: The findings of the study showed that SES is associated strongly with the environmental domain \( r^2 = .421 \) (<.001), marital satisfaction with the social domain \( r^2 = .394 \) (<.001), and PDDs' subtype with the psychological domain \( r^2 = .283 \) (<.001). Mothers of children with autistic disorder subtype reported lower QOL in all domains compared with other subtypes \( p < .05 \).

Conclusion: The determinants such as SES, marital satisfaction, and subtypes of PDDs have an important influence on QOL of mothers of children with PDDs. Further investigation in this regard is warranted.

Copyright © 2013, Elsevier (Singapore) Pte. Ltd. All rights reserved.

* Corresponding author. Musculoskeletal Rehabilitation Research Center, Occupational Therapy Department, School of Rehabilitation, Ahvaz Jundishapur University of Medical Sciences, Ahvaz, Iran.
E-mail addresses: mahany2002@yahoo.com, mahany@ajums.ac.ir (M. Khayatzadeh Mahani).

1569-1861/13 $36 Copyright © 2013, Elsevier (Singapore) Pte. Ltd. All rights reserved.
http://dx.doi.org/10.1016/j.hkjot.2013.03.002
Introduction

Pervasive developmental disorders (PDDs) are defined as organic developmental brain disorders, characterized by abnormal social interactions and communication, as well as a repetitive repertoire of interests and behaviours (Gillham, Carter, Volkmar, & Sparrow, 2000). The definition “PDDs” is actually an umbrella term for the following subtypes: autistic disorder (AD), PDD-not otherwise specified (PDD-NOS), Rett’s syndrome, childhood disintegrative disorder, and Asperger’s syndrome (AS) (American Psychiatric Association, 2000).

The prevalence of all forms of PDDs has been estimated to be approximately 3–6 per 1,000 (Fombonne, 2003), but in various other surveys it is reported to be approximately 7–9 per 1,000 (Fombonne, Simmons, Ford, Meltzer, & Goodman, 2001; Lazoff, Zhong, Piperni, & Fombonne, 2010). There is no documented information about the prevalence of PDDs in our research location. The above raising of the PDDs prevalence, as well as the improvement of community living for people with disabilities over the last decades, has made family the main axis of support to the member with intellectual disabilities (Benjak, 2011).

Although caring for a child is an innate role of parents, providing care for a child with long-term functional limitations is completely different and it impacts all aspects of the parent’s health including physical and psychological health (Raina et al., 2004). Parents of children with PDDs when compared with parents of typically developing (TD) children and parents of children with other developmental disorders reported increased stress (Duarte, Bordin, Yazigi, & Mooney, 2005; Eisenhower, Baker, & Blacher, 2005; Lee, Harrington, Louie, & Newschaffer, 2008; Yamada et al., 2007), more psychological distress (Fombonne et al., 2001; Yamada et al., 2007), more symptoms of depression (Abbeduto et al., 2004; Benson & Karlof, 2009; Lee et al., 2008), decreased quality of life (QOL), and increased levels of physical and mental health problems (Montes & Halterman, 2007; Yirmiya & Shaked, 2005). Mothers of children with PDDs spend significantly more time for childcare and eventually less time in leisure activities (Lampinen, Heikkinen, Kauppinen, & Heikkinen, 2006; Smith et al., 2010). Mothers of children with intellectual disabilities feel more stress than fathers (Allik, Larsson, & Smedje, 2006; Hastings, Beck, & Hill, 2005; Herring et al., 2006), which may be due to their increased involvement in childcare (Hastings, 2003).

Occupational therapy services not only focus on the needs of the children as clients but also on the personal development, QOL, and the needs of the family. Collaboration with the family is essential to understand the daily life experiences of the child. In this regard, assessment of parents in terms of physical, social, and psychological problems is important in a holistic approach (American Occupational Therapy Association, 2010). Therefore, we decided to investigate about the QOL of the mothers of children with PDDs.

There are lots of works in the literature about mothers of children with PDDs in terms of depression, stress, and QOL, but most of them are related to mothers in Western countries. Iranian parents experience different social, spiritual, cultural, physical, and personal contexts. As the context influence the occupational performance (Dunn, Brown, & McGuigan, 1994), the present study is necessary. Because the lower QOL in mothers of children with disabilities has been verified in lots of literature, we decided to find out the factors that influence the maternal QOL. The aim of our study was to examine the association between the determinant factors that influence the maternal QOL including socio-economic status (SES), marital satisfaction, and PDDs’ subtype with QOL in mothers of children with PDDs in Iran.

Methods

Participants

The target populations were all mothers of children with PDDs, aged 2–14 years, in Tehran (Iran). The participants were 210 mothers (mean age: 30.1 ± 5.6 years) of children with PDDs (mean age: 5.1 ± 2.3 years). The participating children were recruited through convenience sampling from regular and special schools, diagnostic clinics, rehabilitation centres, and announcements in Tehran.

The following were the inclusion criteria for the mothers to participate in this study: (a) the age of their children ranged from 2 to 14 years; (b) their children had received a diagnosis of PDDs; (c) had given written consent to participate in the study; (d) reside in Tehran; and (e) no acute changes in health condition or experience of traumatic events, for example, death of a close relative, in the last 2 weeks before the end of the study. The exclusion criteria included the following: (a) World Health Organization QOL-BREF (WHOQOL-BREF) questionnaires missing more than 20% of data and (b) missing Q1 or Q2 items or missing more than two items from the domains.

Procedure

This cross-sectional study was conducted in Tehran, Iran. The study was approved by the ethical committee of the Vali-Asr Rehabilitation Institute. In the first step of the study, the children of potential participants were evaluated. The participating children underwent a comprehensive clinical diagnostic assessment, based on the Diagnostic and Statistical Manual of Mental Disorders (fourth edition, text revision) criteria (American Psychiatric Association, 2000), for verification of their diagnosis and determination of PDDs’ subtype by an expert paediatric neurologist. In the next step, all the included participants filled out a written consent form to participate in the study. A cover page gave information about the study, provided brief instructions, and an example of how to respond to the questions. The demographic information including age, educational level, marital status, child’s age, and gender were then recorded. All participants completed the WHOQOL-BREF (WHOQOL-BREF) questionnaire and the married ones (180 mothers) filled out the Index of Marital Satisfaction (IMS). In the final step, the SES questionnaire was completed by a social worker through interview with every participant.
Instruments

The maternal QOL was assessed by the WHOQOL-BREF questionnaire. It is a 26-item instrument, consisting of four domains, namely, physical health (seven items), psychological health (six items), social relationships (three items), and environmental health (eight items); and two overall QOL (Q1) and general health (Q2) items. The physical health domain includes items on mobility, daily activities, functional capacity, pain, and sleep. The psychological domain measures self-image, negative thoughts, positive attitudes, self-esteem, mentality, learning ability, memory, concentration, religion, and mental status. The social relationships domain contains questions on personal relationships, social support, and sex life. The environmental health domain covers issues related to financial resources, safety, social services, living physical environment, opportunities to acquire new skills, knowledge, recreation, general environment (noise, air pollution, etc.), and transportation. The scores are transformed to reflect 4—20 for each domain, with higher scores corresponding to a better QOL (World Health Organization’s Quality of Life Group, 1996). There is no overall score for the WHOQOL-BREF questionnaire. The questionnaire had been translated into Farsi, and its psychometric properties had been tested. In the test—retest analysis, the intraclass correlation coefficients for the four domains were within the range of acceptable values (physical health = .77; psychological health = .77; social relationships = .75; and environmental health = .84). The concurrent validity of the scales was tested by comparing related domains of WHOQOL-BREF and Short Form-36, which was found to be satisfactory (Nejat, Montazeri, Holakouie, Mohammad, & Majdzadeh, 2008).

The SES was investigated by the SES questionnaire that was customized for Iranian population. The questionnaire revealed good internal consistency reliability (Cronbach’s alpha = .89) (Razavi & Taheri, 2010). It consisted of four domains including educational level, occupational status, income, and housing situation. The highest completed education of mothers in years was considered as educational level. The occupational status of both parents was considered based on the level of skill involved, from unskilled to skilled manual labour to professional. The income level of both parents was calculated in five categories. The type, size of housing, and the total number of rooms were also used as housing situation. After adding the scores of each domain, the total maximum score would be 150. Each participant was categorized into one of the five subgroups based on her total score (150 is divided into five increments of 30) including high, middle to high, middle, low to middle, and low. The questionnaire was filled out by a social worker in a rehabilitation clinic, through face-to-face interview with every participant.

Marital satisfaction was evaluated by the IMS questionnaire that was designed by Walter W. Hudson in 1993. We used its Persian version, which was translated and validated for the Iranian population. The questionnaire received a good reliability (Cronbach’s alpha = .97) and diagnostic validity (.68) (Torkan & Movlavi, 2009), and consists of 25 items presented on a seven-grade scale. The final score of IMS is obtained, by summing up item points. The range of possible total score is from 0 (maximal satisfaction) to 100 (minimal satisfaction). The higher the score, the more dissatisfaction with the relationship. Clinically significant marital dysfunctions are diagnosed at 30 points or more (cut-off point) (Torkan & Movlavi, 2009).

Data analysis

Statistical analysis was conducted with SPSS (version 16.0; IBM Corporation SPSS, Inc.). One-way analysis of variance with Scheffé’s post hoc analysis was used to compare the QOL scores across the three subgroups of PDDs. Multivariate analysis of variance (general linear model) was run to explore the association of SES, marital satisfaction, and PDDs’ subtypes with the four domains of QOL. The coefficient of determination ($r^2$) was used to show the level of association between variables. A p value < .05 was taken to be significant.

Results

Of the 308 potential participants, 51 mothers did not meet the inclusion criteria. Among the 257 included mothers, 47 mothers were excluded, according to the study’s exclusion criteria (respond rate: 81.7%), wherein 22 of 47 did not fill out the questionnaires, 16 of them missed data, and nine experienced acute problems or traumatic events during the last 2 weeks. The children with PDDs were categorized into three diagnostic groups, namely, AD, high-function autism/AS (HFA/AS), and PDD-NOS.

The demographic characteristics of participants are illustrated in Table 1. The results showed significant differences in all domains of QOL among mothers of children with different PDDs’ subtypes ($p < .01$) (Table 2). Scheffé’s post hoc analysis showed significantly lower QOL in mothers of children with AD than the PDD-NOS subtype ($p < .05$). The association of the SES, marital satisfaction, and PDDs’ subtype with the four domains of QOL is shown in Table 3.

<table>
<thead>
<tr>
<th>Table 1</th>
<th>Distribution of Demographic Information in Mothers of Children with PDDs.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mother’s age [Mean (SD) in years]</td>
<td>30.0 (5.0)</td>
</tr>
<tr>
<td>Child’s age [Mean (SD) in years]</td>
<td>5.15 (2.6)</td>
</tr>
<tr>
<td>Child’s gender (boy/girl)</td>
<td>130/80</td>
</tr>
<tr>
<td>Marital dissatisfaction</td>
<td>43 (23.9%)</td>
</tr>
<tr>
<td>Marital status</td>
<td>Married 160 (85.7%); Divorced 24 (12.4%); Widowed 4 (2.9%)</td>
</tr>
<tr>
<td>Educational level</td>
<td>Primary 66 (31.4%); Secondary 93 (44.3%); University 51 (24.3%)</td>
</tr>
<tr>
<td>PDDs’ subtype</td>
<td>AD 94 (44%); PDD-NOS 74 (35%); HFA/AS 42 (21%)</td>
</tr>
</tbody>
</table>

Note. AD = autistic disorder; HFA/AS = high-function autism/Asperger’s syndrome; PDD-NOS = pervasive developmental disorder—not otherwise specified; SD = standard deviation.
According to the study results, the SES had the most significant association with the environmental domain \((p < .001, r^2 = .410)\) and the least significant association with the social domain of QOL \((p = .072, r^2 = .122)\). Marital satisfaction had the most significant association with the social domain \((p < .001, r^2 = .394)\) and the least significant association with the physical domain of QOL \((p = .072, r^2 = .049)\) while the PDDs subtype had the most significant association with the psychological domain \((p < .001, r^2 = .283)\) and the least significant association with the environmental domain of QOL \((p = .042, r^2 = .093)\).

### Discussion

The QOL impairment in families of children with severe disabilities is likely moderated by a complex mixture of environmental and genetically based variables such as SES, social support, and coping strategies \((\text{Raina et al., 2004})\). Contextual factors such as SES; child factors such as behavioural problems, and severity of disability; and intrapsychic factors such as self-esteem, coping strategies, and social supports have all been associated with psychological or physical well-being of parents \((\text{Raina et al., 2004; Vitaliano, Zhang, & Scanlan, 2003})\).

According to our results, the SES had strong association with maternal QOL, especially the environmental domain.

The SES consists of four domains including educational status, occupational status, income level, and housing situation. The environmental domain of QOL consisted of eight questions including (a) security, (b) living situation, (c) financial issues, (d) information accessibility, (e) recreation time, (f) home satisfaction, (g) medical accessibility, and (h) transportation accessibility. The SES and environmental QOL domains fairly correspond with each other. They also correspond with personal, social, economical, and physical contexts, respectively. The contexts play an important role in occupational performance, and therefore the changes in contexts consequently have an impact on the maternal QOL. There is a dearth of literature about the SES and its relationship with QOL of parents of children with PDDs. Consistent with our results, \(\text{Raina et al. (2004)}\) reported that higher SES has been related to fewer psychological life stressors, better emotional well-being in caregivers, fewer child behaviour problems, fewer caregiving demands, and improved psychological and physical health. However, \(\text{Blacher, Shapiro, Lopez, and Diaz (1997)}\) reported that SES may not serve as a buffer against depression in the presence of specific stressors such as intellectual disabilities. The accessibility to free transportation services in Western families may further decrease the impact of SES on parental QOL. Most parents also receive a monthly financial grant to compensate for expenses, which may decrease extreme stress and financial burden in families from the lowest SES groups. However, none of these services exists in Iran and conversely the parents have to pay for therapy services themselves, and therefore the parents from lower SES groups might be more affected. It is suggested to occupational therapists who work with these children and their families to concentrate on empowerment of these susceptible groups in terms of social and psychological support.

According to our results, marital satisfaction associated well with the social domain of QOL. Families of children with PDDs expressed lower level of marital happiness, disturbance of family cohesion, and impairment of family adaptability \((\text{Higgins, Bailey, & Pearce, 2005})\). It has been reported that mothers of children with autism had lower level of marital satisfaction than mothers of children with Down syndrome \((\text{Rodrique, Morgan, & Goffken, 1990})\). The parents of children with PDDs had shown significantly higher divorce rate than parents of TD children \((\text{Freedman, Kalb, Zablotsky & Stuart, 2011; Hartley et al., 2010})\). Parents of children with disabilities might feel pressure from society, especially when their children exhibit unpredictable misbehaviour in public, such as screaming. Parents sometimes refrain from social activities to avoid these
embarrassments. Thus, their social networks will be limited (Leung & Li-Tsang, 2003). At this condition, the only reliable social support for the parents is his or her spouse. Mothers of children with autism spend more time for childcare and eventually less time for intimacy, companionship, and privacy in the marriage (Tunali & Power, 2002). As a result, marital dissatisfaction may occur and the spousal relationship may be decreased. Thus, they may lose their only social support and consequently their QOL (especially the social domain) may be affected. The social domain contains questions on personal relationships, social support, and sex life, so marital dissatisfaction can strongly affect it. Therefore, focusing on child as a client is not sufficient and the whole family members, especially the mother, should be covered in a family-centred approach. Psychological consultation towards increasing marital satisfaction is also recommended for families who are at risk.

The last finding of our study showed lower QOL in mothers of children with AD subtype compared with other kinds of PDDs’ subtypes. The PDDs’ subtypes were also associated with all domains of QOL especially with the social and psychological domains. There are a few studies about QOL of mothers of children with different subtypes of PDDs. Mugno, Ruta, D’Ariggo, and Mazzone (2007) reported lower maternal QOL in HFA/AS compared with the AD subtype, which is not consistent with our results. Gadow, DeVincent, Pomeroy, and Azizian (2004) expressed that children with AD had significantly more compulsions and vocal and motor tics than the PDD-NOS group. Pearson et al. (2006) revealed that children with AD were at particularly high risk for co-morbid behavioural and emotional disabilities. They also mentioned that children with AD compared to individuals with PDD-NOS had more symptoms of depression, social withdrawal, atypical behaviour, and immature social skills, as well as fewer family problems. Because the child’s behavioural problems are the most important predictor of the caregiver’s psychological well-being (Hastings, 2002), lower QOL in mothers of children with AD subtype may be a result of behavioural characteristics of these particular children leading to more parenting stress and stigmatization. If we look at it through contextual models, this corresponds well with personal and social contexts. Child’s behavioural problems in the AD group cause social and personal changes in mother’s life that deteriorates her QOL, especially the social and psychological domains.

This study had several limitations including (a) child determinants influencing maternal QOL such as behavioural problems, severity of diagnosis, and IQ were not considered; and (b) The QOL of mothers was only measured by the WHOQOL-BREF questionnaire, and no physical examination or review of the medical records of the mothers was performed. By contrast, the study also has a number of strengths, namely, (a) adequate sample size, (b) the first study that analyzed the QOL of mothers with PDDs in Iran, (c) investigation about the SES, marital satisfaction, and PDDs’ subtype, which have been overlooked in many literature, and (d) the use of validated measures.

Conclusion

Contextual factors such as SES and marital satisfaction have an important influence on QOL of mothers of children with PDDs, especially the mothers of children with AD subtype. According to our results, among the three SES, marital satisfaction, and PDDs’ subtypes, the PDDs’ subtype seems to be a stronger predictor for the psychological domain; SES for the physical and environmental domains; and marital satisfaction for the social domain in the mothers of children with PDDs. However, further investigation in this regard is warranted.

References


Investigation of quality of life determinants


