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ORIGINAL ARTICLE

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



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KEYWORDS

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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 ($p < .001$, $r^2 = .421$), marital satisfaction with the social domain ($p < .001$, $r^2 = .394$), and PDDs' subtype with the psychological domain ($p < .001$, $r^2 = .283$). 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.

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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.

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