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Parental wellbeing of Iranian families with children who have developmental disabilities



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ABSTRACT

To date, most research with families who have a child with developmental disabilities has been undertaken in English speaking countries. Poorer health, allied with increased levels of stress has been commonly reported for mothers but less is known about the impact on fathers and on overall family functioning. This study aimed to document the correlates of these parental impacts with Iranian mothers and fathers who had children with either intellectual disabilities (ID) or with autism spectrum disorders (ASD). In all 121 parents (69 mothers and 52 fathers from 94 families) who had a child with a diagnosis of ADS, along with 115 parents of children with ID (83 mothers and 32 fathers from 101 families) volunteered to take part in the study. Each participant completed through interview standardised rating scales of parenting stress, emotional well-being, family functioning and satisfaction with caring role along with demographic information and details of informal supports. Structural Equation Modeling identified that family functioning was much poorer in families whose child had ASD and both mothers and fathers reported higher levels of stress. Poorer emotional well-being contributed to higher stress and was more frequent among mothers, single parents and those whose children had behaviour problems. Having other dependents living at home and more sources of informal support improved the emotional wellbeing of parents but not their stress or family functioning. Parents who derived greater satisfaction from their caring role tended to have better emotional health and less stress. Although the impact on Iranian parents of having a child with developmental disabilities is broadly similar to those of parents in other cultures, there are indications that children with ASD present distinct challenges to these families. The model derived in this study is a useful guide both for further research as well as family-centred interventions.

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1. Introduction

Developmental disabilities occur in every culture and every country. It is mostly parents who care for the affected child. In recent years, a growing body of research has documented the adverse impact these children can have on their families, notably in terms of the stresses parents experience and their poorer emotional health. However this research has been undertaken mostly in English speaking, Western countries (Families [Special Interest Research Group of IASSIDD](#), 2013). The purpose of this study was to investigate the well-being of mothers and fathers from another culture; in this instance Iran.

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Iranian society is distinct from other Islamic societies of the Middle-East and Central Eurasia in terms of its long history of civilization, its geographical location, separate language (Persian) and religious denomination (Shia Muslim). Information about the impact of children with developmental disabilities on Iranian parents would assist with the development of more family-centred support services within Iran that are only beginning to develop (Samadi, 2008). It would also offer some insights for supporting Iranian immigrants in Western countries (Welterlin & LaRue, 2007). In addition the study would further confirm if the impact of these disabilities on parental wellbeing is replicated across cultures.

A meta-analysis of 18 studies identified a greatly increased risk of depression among mothers of children with developmental disabilities compared to those with typically developing children (Singer, 2006). Moreover the depression scores of mothers who had children with ASD were also significantly higher than those of mothers whose children had other developmental disabilities (Olsson & Hwang, 2001). The emotional well-being of fathers has received less consideration with no differences reported between parents of toddlers (Davis & Carter, 2008) whereas Jones, Totsika, Hastings, and Petalas (2013) reported that mothers of the same child were significantly more depressed than fathers.

Parental stress also has been a focus of interest with past research consistently reporting significantly more stress among these parents (Pisula, 2011). Mothers have higher stress levels than fathers especially when the child has ASD, although the difference is not so marked with children who have other developmental disabilities such as Down Syndrome (Dabrowska & Pisula, 2010). A clear relationship has been reported between increased parental stress and the severity of behaviour problems exhibited by the child, such as conduct disorders (e.g., Hastings, 2002; Lecavalier, Leone, & Wiltz, 2006; Tomanik, Harris, & Hawkins, 2004).

Only a small number of studies have explored the relationship between emotional well-being and parental stress. Not surprisingly, increased stress is associated with poorer emotional health with stress proliferation over time accentuating parental depression (Benson & Karlof, 2009). More broadly, Smith et al. (2010) suggested that stress is an important predictor of overall family functioning which McConkey, Truesdale-Kennedy, Chang, Jarrah, and Shukri (2008) confirmed in a cross-cultural study with Irish, Jordanian and Taiwanese parents.

A growing literature has identified moderating influences on these adverse impacts. Dempsey, Keen, Pennell, O'Reilly, and Neilands (2009) and Ingersoll and Hambrick (2011) highlighted the role that social support within families can play in moderating maternal stress. Conversely low levels of support have been shown to predict depression and anxiety in mothers (Boyd, 2002) and to result in higher ratings of a negative impact of the child on family life (Bishop, Richler, Cain, Lord, & Floyd, 2007).

More recently attention has shifted to the exploring the gains perceived by mothers of parenting a child with developmental disabilities which can act as an explanatory coping strategy for them (Hasting & Taunt, 2002). There is evidence too that feelings of hope can act as a protective factor against psychological distress (Ogston, Mackintosh, & Myers, 2011).

To date nearly all these research studies have been undertaken with predominantly middle-class, English-speaking, white parents who had access to a range of professional supports for their child (Singer, 2006). The applicability of the findings to parents in other societies around the world cannot be assumed (Ghosh & Magana, 2009). For example, societal influences may affect the way parents appraise the stressors they experience and their styles of coping (Dyches, Wilder, Sudweeks, Obiakor, & Algozzine, 2004). Indeed there is a growing appreciation of the need in Western countries to adjust family support services to the eco-culture of immigrant families (Welterlin & LaRue, 2007) especially if there is an increased likelihood of autism occurring immigrant among families as a recent review suggests (Fairthorne, Langridge, Bourke, & Leonard, 2013). Moreover this argument carries even greater weight when it comes to developing services in non-Western societies (Samadi & McConkey, 2011). These need to reflect the values and cultures of the society and families identified through indigenous research (Crabtree, 2007).

Nonetheless, similar findings to those noted for Western countries have been reported in studies recently conducted in Japan (Mori, Ujiie, Smith, & Howlin, 2009), Malaysia (Norizan & Shamsuddin, 2010), Taiwan (Gau et al., 2012) and Turkey (Bilgin & Kucuk, 2010); notably high levels of emotional problems among mothers whose children had developmental disabilities such as ASD and Down Syndrome which was exacerbated by the child's behaviours. Differences between mothers and fathers have been rarely studied internationally although with Taiwanese families mothers were more affected than fathers (Gau et al., 2012). However no differences were reported between Israeli parents in levels of child-related stress (Rimmerman, Turkel, & Crossman, 2003); a finding also confirmed with Lebanese parents of children with intellectual disabilities (Azar & Badr, 2010). In both these studies, less stress was associated with access to informal support; a relationship also endorsed with Arab mothers of children with intellectual disabilities living in Northern Israel (Duvdevany & Abboud, 2003) and mothers of children with autism living in the West Bank (Dababnah & Parish, 2013). Reports from Turkish mothers as to how they coped with stress arising from a child with ASD also confirms the contribution of social support (Bilgin & Kucuk, 2010).

The present study focused on Iran: a culture that thus far has received little international attention. However it sought to integrate into one investigation the various pertinent parameters identified in previous research with families. Thus the main aims of the study were:

1. To describe the inter-relationships between emotional health, parenting stress and family functioning with Iranian parents.
2. To compare the impact on parental wellbeing of having a child with intellectual disability (ID) with children who have a diagnosis of autism spectrum disorder (ASD).

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