

Predictors of stress in mothers and fathers of children with fragile X syndrome

Annette McCarthy^a, Monica Cuskelly^{a,*},
Christina E. van Kraayenoord^a, Jonathan Cohen^b

^a *School of Education, The University of Queensland, Brisbane, Qld. 4072, Australia*

^b *Monash University Department of General Practice, Centre For Developmental Disability
Health Victoria, and Fragile X Alliance Inc., Melbourne, Vic., Australia*

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Abstract

This study examined parental and family stress and functioning where there is a child with fragile X syndrome. Mothers and fathers in 40 families were asked about their child with fragile X syndrome, family supports, their psychological stress, the marital relationship, and their family stress. Results indicate parents were well adjusted in terms of their levels of psychological stress and in their marital relationships, however, parents reported high levels of family stress. Mothers and fathers were found to experience similar levels of stress and to report similar levels of satisfaction with supports. Stress was predicted by different variables in mothers and fathers, suggesting that different processes underlie their experiences. The strongest predictor of maternal stress was the level of marital satisfaction while the strongest predictor of paternal stress was the level of the child's adaptive skills.

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Fragile X syndrome is the most common inherited form of intellectual disability, with an estimated incidence of 1 per 2000–4000 in the general population (Eliez & Reiss, 2000; Hagerman, 1997). It is an X-linked genetic condition that manifests in a variety of ways, with affected individuals presenting with a range of developmental, physical, behavioural and emotional characteristics (Lennox, Cohen, Slater, & Cook, 1998). The additional demands associated with the consequences of these characteristics may mean there is increased strain on parents.

* Corresponding author.

E-mail address: m.cuskelly@uq.edu.au (M. Cuskelly).

While parental functioning has been extensively examined in families with a child with a disability (e.g., Cuskelly, Jobling, Chant, Bower, & Hayes, 2002; Ricci & Hodapp, 2003; Roach, Orsmond, & Barrett, 1999), few studies have investigated parental experience specifically in families where there is a child with fragile X syndrome. When researchers have explored this area they have generally focused on the impact on parents of the diagnosis of fragile X syndrome (e.g., Bailey, Skinner, Hatton, & Roberts, 2000; Carmichael, Pembrey, Turner, & Barnicoat, 1999; Roy, Johnsen, Breese, & Hagerman, 1995). The examination of parental functioning within specific aetiological groups makes an important contribution to the literature as it is clear that parental experiences differ, depending upon the cause of their child's disability (Abbeduto et al., 2004; Fidler, Hodapp, & Dykens, 2000). It is particularly important in the case of fragile X syndrome as there is evidence that mothers of a child with fragile X may themselves have characteristics that make them vulnerable to the effects of increased child care demands (Reiss, Freund, Abrams, Boehm, & Kazazian, 1993).

While stress is not the only impact on parents of having a child with a disability, it is one of the constructs central to our understanding of their experience and of parental functioning. In essence, stress is a negative (usually, but not restricted to) psychological response to demands that are perceived to be greater than the resources available to meet them (Lazarus, 1993). The experience of stress may be manifested in a range of ways and researchers have operationalized it variously, including depression and anxiety (Spangenberg & Theron, 2001), negative impact on parents (Baker, Blacher, Crnic, & Edelbrock, 2002; Hodapp, Fidler, & Smith, 1998), and psychosomatic symptoms (Sloper, Knussen, Turner, & Cunningham, 1991). Higher levels of stress have consistently been found to occur among parents of a child with a disability when they are compared to parents whose children are all developing typically (see, for example, Cuskelly et al., 2002; Hodapp, Dykens, & Masino, 1997).

The higher levels of stress found in parents of children with a disability have been assumed to be a product of the increased demands they experience. These increased demands arise from the care needs of the child and the necessity to interact with and manage the child's environment (broadly defined and including hospitals, therapy settings and schools) in order to have the child's needs met. Both these areas of demand may be affected by the nature of the child's disability.

There is substantial evidence that the aetiology of the child's disability is an important variable in parental stress (Hodapp et al., 1998; Hodapp, Wijma, & Masino, 1997). Some disabilities are consistently associated with greater parental stress than others. For example, in a number of studies, parents of a child with Down syndrome have been found to experience lower levels of stress than do parents of children with autism (e.g., Hoppes & Harris, 1990; Kasari & Sigman, 1997). In a recent study comparing mothers of children with Down syndrome, fragile X syndrome, and autism, Abbeduto et al. (2004) found that mothers of a child with fragile X syndrome displayed lower levels of well-being than mothers of children with Down syndrome, but higher levels than mothers of children with autism.

It is likely that these differences in parental stress are due to differences in child attributes that are associated with the aetiology of the disability. Children with an intellectual disability present with more difficult behaviour than do typically developing children (Baker et al., 2002; Dekker, Koot, van der Ende, & Verhulst, 2002) and children with Down syndrome generally have fewer behaviour problems than children with an intellectual disability from other causes (Dykens & Kasari, 1997; Einfeld, Tonge, Turner, Parmenter, & Smith, 2000). This is not to suggest that behaviour is the only difference between these groups, nor that behavioural problems are the only cause of parental stress, however, behavioural problems are clearly one of the main predictors of stress in parents (Baker et al., 2002; Hastings, 2002).

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