Chapter 6

Stress and Resilience in Parents of Intellectually Disabled Children

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ABSTRACT

The present study is an attempt to find out the factors of stress that could act against the resilience in the parents of intellectually disabled children. The sample consisted of 50 parents of intellectually disabled children from different panchayats in the Calicut, Kannur, Wayanad districts in the state of Kerala, India. Resilience in the parents was measured using “Bharathiar University Resilience Scale” developed by Annalakshmi (2009). To measure stress among the parents “Stress Scale for Parents of mentally challenged (SPMC)”, developed by Rejitha, Biji and Jayan (2005) was used. As per the results, extra-familial stress was a negative predictor of resilience in the parents of the intellectually disabled children. Results further indicated that the parents who were in a late part of the young adulthood period and old were relatively more resilient than the parents who were in the earlier part of the young adulthood period.

INTRODUCTION

Raising a child with an intellectual disability is a stressful experience for parents (Khadi & Hidangmayum, 2012). Numerous psychological and social factors contribute to this distress (Gohel, Mukherjee, & Choudhary, 2011). It starts by the birth of such a child, which is considered as an accident faced by the family. Initially, it will be difficult to accept as a reality. Later, during the commencement of acceptance, parents and close relatives will start formulating different complex speculations regarding the observation of the society on them. Intrapersonal and interpersonal responses to the accepted reality are deeply associated with their identification regarding these speculations as either true or false. These speculations, as well as certain stressors, will together intervene in such a way that it would reduce hope and expectations and ultimately, the self-esteem of the parents. Distress in the parents is thus multidimensional, and the whole of this distress is more than the sum of its parts.

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Major stressors faced by the parents include problem behaviours of the children, financial difficulties, the dilemma to face the professionals, flaws in one’s own parenting style etc. Among these, the most prominent stressor that negatively influences the quality of life of the parents is the problem behaviour of the intellectually disabled children (Mulder, Tudor, & Walsh, 2013). According to Gohel, Mukherjee and Choudhary (2011), one of the commonly held thoughts to avoid this stressor is by separating the child from the family. There are also parents who had reported high suicidal ideation due to this stressor. The problem behavior is a factor that has the capability to moderate pain among the parents and their stress. Significant interaction effects have been identified between these two factors.

Other most important stressor is financial difficulties with regards to the treatment of the child which are typically expensive (Serrata, 2012). In a country like India, therapeutic supports for the intellectually disabled children from psychologist and related professionals are not yet fully recognized. Financial support from the part of the government seems to be more biased to the special education sector, which can only make very little contribution to the cognitive and intellectual advancement in the children. Hence, parents have to depend on their own daily income to provide necessary therapeutic provisions.

For some of the parents, however, managing child care routines and day-to-day household tasks are not as stressful as the interactions they had to make with the school and mental health professionals (Singer and Todis, 1991). Even though inclusive education methods are encouraged, many of the private sector schools hesitate to make it a choice for practice. Reduced academic performance of the children will be considered as a sin in at least some of the institutions. Parents also will be showing reluctance to accept the reality that their children are not pacing up with the peers.

Mulder, Tudor and Walsh (2013) reported that an overprotective parenting style is sometimes a stressor for the parents themselves. Diagnosis of disability in the children will make some parents to act overprotective. This may bring a sense of crisis in each and every behaviour modulations in their children. However, stress and resilience among the parents may differ with respect to the disorder. For instance, according to Abbeduto, Krauss, Murphy, Orsmond, Seltzer and Shattuck (2004) mothers of fragile X syndrome children have reduced levels of well-being when compared to the mothers of down-syndrome children, but increased levels related to the mothers of autistic children. Hence, the disorder itself may be considered as one of the stressors.

Behavioural responses of the parents of intellectually disabled children to their experiences of stress used to vary. In general, they are reported to undergo high levels of frustration and dissatisfaction (Heiman, 2002). Heavier does the daily stressors and hassles, greater will be the tendency among the mothers and fathers to view their marriages negatively. (Gavidia-Payne & Stoneman, 2006). The inverse correlation between stress and marriage quality in the parents with autistic children has been noted by Serrata (2012) also. In the study by Ahmedani and Hock (2012) exclusively among the parents of the children with autism spectrum disorder, lower levels of relationship satisfaction were identified. Negative marital interaction and low relationship satisfaction among the parents could result in an unconstructive relationship with the children (Floyd & Zmich, 1991). However, this will not be reflected in their self-reports (Floyd & Zmich, 1991).

Ahmedani and Hock (2012), when compared the social and ecological contexts of the parents, understood that they are poor in maintaining the social capital, especially in their relationship with the neighbors. Their social participation and employment status seemed to be lower when compared to the parents of the normal children, even though they were similar in education, physical health and marital status (Floyd, Greenberg, Hong, Pettee, & Seltzer, 2001). As the protective factors associated with the social support is lacking, they have a high proneness to psychosocial problems (Serrata, 2012), when