Chapter 5
Role of Stress and Age in Resilience Among Parents of the Children with Intellectual Disability

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ABSTRACT

Parents of children with intellectual disability face various stressful situations. However, many of them show resilience even in the midst of challenges and are able to meaningfully contribute to the life of the child. In the present study, the factors of stress that hinder resilience are assessed in a sample of 50 parents of intellectually disabled children. Stress scale for parents of mentally challenged (SPMC) developed by Rejitha, Biji, and Jayan was used to measure the stress of the parents. Resilience was measured using the Bharathiar University resilience scale, developed by Annalakshmi. Results showed extra-familial stress as a significant inverse predictor of resilience. Older parents are relatively more resilient when compared to the younger.

INTRODUCTION

Raising a child with an intellectual disability is a stressful experience for the parents (McConnel & Savage, 2015; Khadi & Hidangmayum, 2012). The birth of the child would be like an accident happened in the family (Walsbren, 1980). Initially, parents would have difficulty to accept reality. Later, when they were ready to accept, close and distant relatives would formulate intricate speculations regarding the associated reflections and stigmatizations in the society. Interpersonal and intrapersonal responses of the parents to the accepted reality depends on how much they identify these speculations as true or false. Along with the speculations, various other stressors related to the parent-child relationship will together interplay in bringing down the hope and expectations and ultimately, the self-esteem of the
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parents. Distress in parents, as a whole, is multidimensional and more than the sum of its parts (Gohel, Mukherjee, & Choudhary, 2011).

Stressors faced by the parents include comments by others on the errors committed by them to have such a child, remarks by the observers on the deficits in the child and flaws in parenting, stigmatization while attending the public functions, dilemma in facing the mental health professionals, financial difficulties due to the investment in the treatment, behaviour of the child and so on (Minnes, 1988; Dervishaliaj, 2013). All these factors are potential inverse contributors to the low quality of life of the parents. The most predominant among these is the problem behavior of the child (Mulder, Tudor, & Walsh, 2013), which acts as a moderator in the relationship between pain experienced by the parents and their stress. To prevent this stressor, parents may show a tendency to separate the child from the family. Some parents had reported high suicidal ideation due to this stressor.

Another most recurrently observed stressor is financial difficulty (Serrata, 2012). The treatment, as there are no medicines but only behavioral interventions that demand longitudinal care, which costs more than half of the income of a middle-class family in a country like India. Moreover, a significant chunk of the population and the policymakers are not yet aware of and convinced with the role of psychology and allied science professionals in modifying the behavior of the child with different abilities. Financial support from the part of the government seems to be more towards the special-education sector, which is also important but can only be effective when accompanied by the support of psychotherapy, occupational therapy, speech therapy. Hence, parents are compelled to spend a considerable part of their income on providing the therapies that help their child to achieve acceptability in the mainstream. Those who are from the moderate and low-socioeconomic background the expenses are unaffordable.

Some parents are stressed while taking the child to a mental health professional (Singer and Todis, 1991). They fear stigmatization by the public. By the time, they might have already reformulated and readopted their roles and identities as the parents of children with intellectual disability (Walsbren, 1980). Observation of the public on the challenging behavior and self-mutilation of the child resulting in the comments and comparisons with mainstream lead the parents to experience the stigma, rather than the child (Dervishaliaj, 2013). While explaining the issues related to the behavior of the child to the professional, they re-experience this stigma and hence get stressed.

Some of them fear the change in the behavior of the child due to the exposure to the other disabled children in the mental health center. They were also anxious about the care, given by the professionals to their child, as there are more such children in the center. As the children demanded constant care (Minnes, 1988), they tend to continue committing most of their time and energy in caretaking. While leaving the child in the mental health center makes them feel insecure, as the child is not with them for some time. This feeling of insecurity will persist until they develop a convincing and good relationship with the mental health professional.

There are situations when parents change the therapists recurrently due to this feeling of insecurity. They will be doubtful regarding the perception of the professional on the child’s disability. While interacting, they will constantly be looking at the signs and reflections, which they can relate themselves with the professional. Whenever there is a gap in this relatedness, a lack of trust emerges. The recurrent feeling of the breach in the trust would lead to show the tendency to quit and approach a new professional.

Constant care for a period of time, and the dependency of the child may lead to an unhealthy attachment style between the parent and the child (Mulder, Tudor, & Walsh, 2013). Parents might have started considering their child as a part of themselves. They fear to expose the child to an inclusive classroom, as they are anxious about the stigma that will be experienced by their child from their classmates as