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Understanding Stress and Resilience in Families of Children with Down Syndrome

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ABSTRACT

Stress is defined as the body's physical and emotional response to perceived threats or challenges. Stress can manifest positively (eustress) or negatively (distress) and is caused by biological, psychological, and social factors. The birth of a child with Down syndrome can lead to emotional changes, such as uncertainty and concern, which cause stress for parents and siblings alike. Families with a child with Down syndrome experience significantly higher stress levels than families without children with disabilities. However, stress levels can vary among family members. Additionally, the effectiveness of psychological interventions aimed at parents can vary significantly due to differences in cultural context and specific family variables. This study addresses

the multifaceted nature of stress in families with children diagnosed with Down syndrome. It focuses on psychological, behavioral, and family dynamic factors affecting the well-being of parents and siblings.

Keywords: Down syndrome, stress, resilience, parental care, family

INTRODUCTION

Stress can be defined as the body's physical and emotional response to situations that are perceived as threatening, challenging, or novel. This reaction is considered natural in response to stimuli that require adaptation. However, when it is excessive or prolonged, it can have negative effects on health[1]. Stress is a multifaceted phenomenon that can be divided into acute or chronic. It is also often classified as eustress (positive) or distress (negative)[2]. Stressors or triggers of stress responses can be biological, psychological, acute, chronic, environmental, internal, or psychosocial in nature and are often grouped into four domains: the first is physical, the second is psychological, the third is psychosocial, and the fourth is psycho-spiritual[3].

Down syndrome (DS), also known as trisomy 21, is the most prevalent genetic disorder in the human population and is identified as the leading clinical cause of intellectual disability[4]. The global prevalence of the condition is estimated at approximately 1 in 700 live births. In the Mexican context, the prevalence has been calculated at 3.7 cases per 10,000 births[5]. The birth of a child with DS tends to elicit a wide range of emotions in the family environment, including uncertainty and concern about their care, education, and upbringing. This situation is mainly attributed to the intellectual disability associated with this syndrome[6]. Furthermore, the development of specific traits characteristic of children with DS, such as distinctive behavior patterns, temperament, and varying degrees of cognitive impairment, can contribute to increased levels of family stress, which in turn can lead to changes in family dynamics[7,8].

Parental stress and Down syndrome

Studies on families of children with DS have identified particular patterns of stress and adaptation that differ from those observed in families with children who have other developmental disorders[9]. One of the most critical moments is the diagnosis, which is often a highly stressful experience for parents[10]. The way in which the news is communicated has a considerable influence on the emotional experience: it is often delivered without sensitivity or empathy, omitting positive aspects of DS[11]. This generates intense feelings such as surprise, pain, distress, denial, sadness, fear, and anxiety, especially among mothers.

In many cases, mothers are also blamed by the medical or family environment, either because of their age or because they did not detect the condition during pregnancy, which intensifies their emotional burden. In addition, some women face motherhood alone, due to abandonment by their partner or lack of support from the paternal family[8,12]. The arrival of a child with a disability can be experienced as a trauma that disrupts family dynamics and forces a long and complex process of adaptation, which varies according to the individual characteristics

of each family and the type of disability of the child. In the specific case of DS, stressors include, in addition to the impact of the diagnosis, the frequent presence of health problems that require constant medical attention and hospitalizations, as well as difficulties in the child's cognitive and behavioral development[13].

Although families with children with DS tend to experience higher levels of parental stress compared to those with typically developing children, some studies indicate that this stress is lower than that reported by families of children with autism, Attention Deficit Hyperactivity Disorder (ADHD), cerebral palsy, or other genetic syndromes[14-20]. For example, mothers of children with Williams syndrome tend to report even higher levels of stress, associated with characteristics such as hyperactivity and emotional instability[16,21].

In general, mothers of children with intellectual disabilities face greater difficulties in accepting their children's condition than those with neurotypical children. Parental stress in these cases has been associated mainly with the severity of the disability, the presence of problematic behaviors, and certain personal factors of the parents, such as locus of control, family cohesion, optimism, and resilience[16,22,23].

The age of the child also influences: parents of young children tend to report more unmet needs than those with adult children[24]. On the other hand, access to social support networks and the use of effective coping strategies are associated with lower levels of parental stress[25]. Although both parents may experience similar levels of stress, there are significant differences. Mothers tend to report more depressive symptoms and a lower sense of parental competence, while fathers tend to be more affected by the severity of the diagnosis and maladaptive behaviors. However, greater involvement in the care of the child is associated with a stronger emotional bond and a greater perception of self-efficacy[18,26].

Taken together, these findings underscore the need to consider both maternal and paternal experiences, as well as the individual characteristics of the child, when assessing family functioning. They also highlight the importance of designing specific, developmentally and contextually sensitive interventions that provide effective support to families of individuals with DS and other developmental disabilities.

Stress among siblings with Down syndrome

Studies on the stress perceived by siblings in family environments with children diagnosed with DS have yielded contradictory results. Some studies report no significant differences in behavioral problems between siblings of children with DS and siblings in comparison groups[27]. Other research highlights the importance of family variables in the well-being of siblings[28]. In general terms, siblings of children with DS tend to exhibit positive self-concepts and strong social competence[28].

However, high parental stress in families with DS can indirectly affect siblings[27]. In contrast, siblings of individuals with autism exhibit significantly higher levels of general stress compared to siblings of children with DS[29]. Various family factors, such as demands, available resources, communication styles, and coping strategies, are closely interconnected with the well-being of siblings in families with DS[28]. These findings highlight the urgent need to consider family dynamics as a whole, as well as the specific characteristics of the disability, when addressing stress among siblings in the context of families with children with developmental disabilities.

Family resilience and Down syndrome

Research conducted on families with children with trisomy 21 has identified several factors that influence resilience and adaptation. Family cohesion, communication skills, and strength have been shown to have a positive impact on family adjustment. On the other hand, parental depression and poor communication have been identified as factors that negatively affect family adjustment[30,31]. Siblings of children with DS tend to exhibit positive self-perception and social skills, influenced by variables such as family demands, available resources, problem solving, and coping strategies[28]. In terms of mental health, children with DS exhibit relatively low rates of serious problems, although in adulthood there is an increased risk of depression and Alzheimer's disease. However, evidence in adolescents with DS remains limited[32]. To strengthen family resilience, interventions should focus on reducing depression in caregivers and improving family cohesion and communication[30,31].

Psychological interventions for parents of children with Down syndrome

In this context, studies on psychological interventions aimed at parents of children with DS have yielded mixed results. Mothers tend to experience increased stress levels over time, influenced by the child's cognitive-linguistic development and behavioral problems[17]. However, several studies have shown that educational interventions can have a positive impact on knowledge, psychological well-being, and coping strategies[33]. Ego resilience has been identified as a mediating factor between perceived stress and psychological well-being; parents who more positively perceive their role report greater well-being[34]. However, the effectiveness of interventions is not uniform. A study conducted in Pakistan found no significant relationship between involvement in parenting programs and reduced stress, although it did observe a slight positive impact in the social sphere[35]. These findings call attention to the importance of designing culturally sensitive approaches tailored to the specific context to provide effective support to parents of children with DS.

CONCLUSIONS

The reviewed findings highlight the intricate interaction between child characteristics, parental resources, and family dynamics in shaping families' experiences of stress when they have a child with DS. While some parents report experiencing greater self-efficacy and a positive outlook on parenting, a significant proportion continue to face persistent challenges related to the demands of caregiving and behavioral problems. Interventions that promote family cohesion, which have been shown to reduce parental depression and improve communication and coping skills, could improve outcomes, although they need to be adapted to cultural and contextual factors.

Consequently, future efforts should focus on implementing comprehensive, culturally sensitive support strategies that address the needs of all family members, including parents, siblings, and children with DS, at all stages of development and life transitions.

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