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Emotional Burden and Copying Styles in Parents of Children with Down Syndrome

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Abstract

Down syndrome (DS) varies in severity among people with Down syndrome, causing intellectual disability and lifelong developmental delays. It is the most common genetic chromosomal disorder and causes learning disabilities in children. It also frequently causes other medical abnormalities, including heart and digestive disorders. The role of a parent with a disabled child can be very demanding. There are few publications regarding the emotional burden and coping patterns of parents. The aim of this research was to identify the motional burden and coping styles in parents of children with Down syndrome. This study showed that mothers of children with DS are more prone to emotional exhaustion and depression than their partners, thus, efforts to prepare and educate them in effective coping strategies can modify the way they value the relationship with their children and make a positive impact in the process of raising their children with DS. Additionally, this research suggests that mothers should be given opportunities to engage in certain professional activities that can give them resources to meet the daily challenges of having a DS child at home.

Keywords: *Emotional Burden, copying styles, Parents, Down syndrome, Trisomy 21*

1. Introduction

Down syndrome (DS) or trisomy 21, as the most common cause of mental, developmental, and educational disabilities, is caused by genetic disorders. Individuals with DS face many health-related issues, such as delayed motor neuron development, impaired cognitive function, and poor hand-eye coordination (Lara & de los Pinos, 2017). Life, and associated coping and coping strategies adopted by their families were studied (Bray, 2017). The results showed that in addition to reduced quality of life, they required long-term care services (Kashi, 2015).

Studies have reported that stress is an important factor affecting the function of families of children with intellectual disabilities (Smith, 2010). Although social support can play a critical role in reducing parental stress (Dempsey, 2009), more than 60% of families of children with intellectual disabilities, intellectual disabilities and DS do not have adequate social support (Gholami, 2018). While these families suffer from many social problems, these families adopt specific strategies to meet the needs of their lives so that they can deal effectively with the challenges associated with the birth of a disabled child. A study reported that promoting hope could act as a supportive factor against mental disorders in these families. The family is the core of the care and upbringing of children with mental and physical disabilities. The health of the family is an integral part of the health of its members, and the community (Lara & de los Pinos, 2017).

There are few studies on the effects of caring for children with DS on families' quality of life and their coping strategies. Mothers of children with DS have been reported to have lower environmental and mental health status. Moreover, negative attitudes of society towards children with disabilities, economic issues, and insufficient support affect the quality of life in the family (Abbasi, 2016). It has been revealed that children with DS have a full range of social, behavioral, and physical problems and that their parents have psychological problems. Their mothers often receive little support from others and their siblings receive less support than their mothers. Therefore, there is a need to make routine changes to meet the needs of the family. Some families of children with DS may use flexibility and coping skills (Van Riper, 2007).

Other families may acquire adaptive skills by being optimistic about their future lives, accepting their children's condition, making changes in their routines (King, 2009), and using coping strategies focused on emotion to deal with stress (Dabrowska & Pisula, 2010). Several studies have examined coping strategies in families of children with DS and also the effects of behavioral and mental problems associated with this problem (Lara & de los Pinos, 2017). These studies mostly used quantitative designs and ignored the live experiences of families (Gashmard, 2020). Therefore, the aim of this research was to identify the emotional burden and coping styles of parents of children with Down syndrome through the theoretical side and previous studies related to this topic.

2. Down syndrome

Recently, interest in studying disabilities in children and the role of parents in adapting to them has increased. International institutions have dedicated special clauses in their literature and decisions related to disability, and established international councils and bodies specialized in the disabled.

Therefore have governments in most countries of the world, and their ministries have departments to follow up on the affairs of people with special needs. In addition, special institutions appeared in societies to defend the rights of the disabled and to provide the necessary rehabilitation services and programs for them, and specialists and researchers studied the causes, manifestations, methods of treatment and rehabilitation methods for various disabilities, and our Arab societies had a share of all this (Abbasi, 2016). More than a hundred years ago, the scientist Down described children born with distinctive features, the most important of which are tilted eyes, a relatively small round head, short hands, and some special features. These children show a slowdown in their motor development, which subsequently develops into a form of mental retardation, and in the year scientists discovered the chromosomal defect that causes the disease, the disease has long been known as the (Mongolian) child disease, a misnomer that is not used scientifically and has no justification (Gashmard, 2020).

Down Syndrome: It is a syndrome of mental retardation (from mild to severe) associated with multiple disabilities resulting from the presence of the chromosome three times instead of twice in some or all human cells discovered by the English scientist (Down. H. L. J). This condition is characterized by a general delay in growthو flat face, shortening of the skin thread that connects the upper eyelid to the eye, protrusion of the lower lip of the mouth, small round ears with abnormalities in the outer ear, rough and cracked tongue, pointed hands and feet, short fingers and crooked ring fingers, various degrees of hearing loss, as well as disturbance in the speech process (Nicolosi & Harryman, 1989).

Down syndrome is a complex and common congenital anomaly of the chromosome as a result of an imbalance in cell division and is associated with mental retardation. It was first identified and described in 1966 by the physician John down Langdon John. Down syndrome is a genetic disorder that causes an increase in the number of chromosomes from 46 to 47, when abnormal cell division occurs in the genetic material of chromosome number 21. This genetic disorder varies from child to child in severity, causing intellectual disability, lifelong developmental delays, and learning difficulties in children with it. Early intervention for people with Down syndrome can greatly improve the quality of life for children and adults with this disorder and help them to coexist with society (Abbasi, 2016).

Down syndrome is a congenital condition, meaning that it is in the child since birth and that the condition has been in him since the moment he was born. It is caused by an increase in the number of chromosomes. And chromosomes are small bacilli inside the nucleus of the cell, and these chromosomes carry within them the full details of human creation (Larayedh, 2003).

The real causes of Down syndrome are unknown. There is only one scientifically proven relationship, which is the association of this syndrome with the age of the mother. The older the woman, the more likely the child will be born with Down syndrome, and the more likely it is if the woman is over 35 years old. But this does not mean that women younger than 35 years of age do not give birth to children with Down syndrome (Kashi, 2015). In fact, most children with Down syndrome were born to mothers under the age of 35, and this is due to the generally higher number of births for mothers who are under 35 compared to older women. And if we know that a woman is at any time at risk of giving birth to a child with Down syndrome, the number (not the percentage) of children with Down syndrome for young women will be greater than that of older women (Al-Arir, 2010).

People with Down syndrome are characterized by these or some of these physical characteristics: an abnormally small chin (Weiss, 2009), a transverse tilt in the cleft of the eye with excess skin in the inner corner of it called the epicanthal fold, also known as the Mongolian fold, poor muscle tone, and flatness In the bridge of the nose, only one fold in the palm of the palm, and a protrusion in the tongue due to the smallness of the oral cavity and the enlargement of the tongue, which makes it close to the tonsils in the throat (Bray, 2017), and shortness in the neck, and the presence of white spots in the iris known as Burchfield spots (Dabrowska & Pisula, 2010), and relaxation Excessive laxity of the joints includes looseness and instability of the anorexic joint, congenital defects in the formation of the heart, enlargement of the space between the big toe and the next, a single fissure and contracture in the fifth toe, and a greater number of fingerprint zigzags. The majority of people with Down syndrome have mental retardation, ranging from mild (IQ 50–70) to moderate (IQ 35–50). The IQ of individuals with Mosaic Mogul usually increases between 10-30 points higher. In addition, people with Down syndrome may have dangerous and abnormal changes that affect the body's systems, and they may have a wide head and a very round face. Or they may be characterized by baldness (Yang, 2002).

Medically; the consequences of the abnormal increase in genes (genetic material) in Down syndrome are large and very different and may affect any body functions, systems or the way it works. The correct treatment of the disease includes awareness and readiness to prevent any negative impact, as well as awareness of all the problems and complications that result from the genetic disorder, control and the ability to manage the accompanying symptoms, and helping the affected person and his family to adapt and succeed in overcoming all the difficulties related to the disability associated with the health condition (Gashmard, 2020).

3. Emotional burden and copying styles in parents of children with down syndrome

3.1 Emotional Burden in Parents of Children with down syndrome

The upbringing and upbringing of children in general is a great responsibility, and bearing the responsibility for a man to be a father and for a woman to be a mother is a heavy and difficult matter that requires a lot of psychological, cognitive and material preparations. It entails problems and effects whose psychological effects cannot be overlooked, given the deep psychological wounds it leaves for all family members. Disability constitutes one of the challenges facing the family, especially the parents, and is considered one of the most important and greatest pressures faced by the family on the social, psychological and economic levels. Therefore, many of the reactions, particularly by the parents, are clearly manifested as a result of the emergence of disability within the family, after the diagnosis of the child's condition by specialists. The parents have special feelings and feelings that crystallize within stages of reactions (Gashmard, 2020).

Disability, which represents the slow growth of the child and special measures required for physical care, training, health and follow-up to him, these matters are accompanied by disappointment and loss of dreams, all of this creates pressures that affect the family balance, and may be added to these pressures financial distress and tensions resulting from the immature control of the child over The same, and the child’s difficulty communicating with the family and with those around him, in addition to the doubts of parents regarding their method of upbringing and the appropriateness of their methods for the child’s disability, and thus the relationship between a disabled child and the family is more exposed to complexity, hesitation, and more tense and continuous than the normal relationship (Abdelall, 2021). The psychological pressures of parents of the disabled express the bad influence and emotional burden caused by the presence of a disabled child or the negative characteristics of the parents, which provokes them undesirable mental, emotional or organic reactions, exposing them to tension, distress, anxiety, sadness and grief, as they may suffer from it. Some of the psychological and physical symptoms exhaust their energies and prevent their ability to focus on their work (Jaramillo, Moreno, & Rodríguez, 2016).

The frequency of Down syndrome (DS) in Colombia has been reported between 16.3 and 17.8 per 10,000 live births (Zarante et al., 2010), and the disorder ranks third in frequency among congenital malformations over national level. Children with this genetic condition not only have mental impairment, but also other types of disabilities or abnormalities (Bull & the Committee on Genetics, 2011). Since the 1970s, it has been recognized that all such patients require careful and rigorous care by another person, usually a parent (Ryde-Brandt, 1988). The burden of caring for a disabled child appears to increase with having to give up his job, a lack of social interaction, and the realization that the child's condition will not improve (Dabrowwska and Besola, 2010).

Some authors have suggested that motherhood, regardless of the child's status, is a major risk factor for stress due to responsibilities in the care and education of children (Akgün, 2014). A recent meta-analysis suggested that parental stress is higher in fathers of children with autism spectrum disorders or DS than in parents of typically developing children (Hayes & Watson, 2013). Other studies have shown that mothers of children with DS have higher stress levels than those of mothers of non-disabled children (Esdaile, 2009). Quantitative and quasi-experimental cohort studies in Latin America found that the perception of fatigue and higher parental demands caused by caring for a child with DS did not change at the time of follow-up. Another important finding is the higher prevalence of fatigue among mothers compared to fathers (Van Der Veek et al., 2009). The results of a study published in 2015 showed that life stress, fatigue and depression are closely related and may share some underlying mechanisms. Depression and emotional exhaustion are associated with the number of life stress events (Plieger et al., 2015).

According to the description given by Procaccini and Kiefaber (1983), parental burnout is a condition resulting from untreated chronic fatigue due to persistent demands on family needs and cessation of non-parental activities, which deplete parental energy and motivation , several studies have investigated the Frequency and severity of the syndrome onset among parents of children with various diseases including type 1 diabetes, irritable bowel syndrome, and parents of CNS tumor survivors (Lindström et al., 2011). Those studies showed an association between a parent's gender and level of emotional exhaustion. A recent study comparing burnout between mothers of children with autism and mothers of children with hearing impairments found that the worldwide frequency of the syndrome is 74.78% (the frequency in mothers of children with autism is 85.74%; mothers with hearing-impaired children 63.81%; t: 7.07, $p < 0.001$;, suggested that a difference in a child's impairment could influence the parents' level of exhaustion (Varghese & Venkatesan, 2013).

The level of physical fatigue in parents of disabled children is related to the availability of social or occupational support networks. Thus, parents with strong social networks adapt better to their children's needs and experience better family functioning and well-being (Cuskelly & Gunn, 2006; Molina & Agudelo, 2006).

Mothers of children with DS have a greater likelihood of fatigue than other fathers. It is important to note that the frequency of emotional exhaustion in families with children with DS coincided with the frequency reported by several studies of families of children with cognitive impairments (Lindstrom et al., 2011). The chance of a mother experiencing emotional exhaustion is 3.6 times higher (95% 1.3 - 9.7) than that of her partner. Some studies have found that the frequency of emotional exhaustion in mothers was twice as high as in fathers (McGrath et al., 2011).

There is a slight association between the presence of depression and emotional exhaustion in mothers, with depression being diagnosed more frequently in the affected group; this finding is similar to the relationship found by Plieger et al. (2015) which shows a moderate association between burnout and depression. Therefore, mothers of DS children should be given priority over fathers in coping programs and psychotherapies (Martinez Fontanilles & Rodriguez Vernal, 2010) and that mothers can benefit from participation in a career outside the home, even if it's a part-time job (Jaramillo et al., 2016).

Although the burden of caring for and raising a child with DS has been heavy, these families can effectively deal with their problems and try to raise their children properly. However, the ability of the family to adapt depends on the support available. The findings of this study have important implications for health professionals, researchers, and policymakers in providing services to children with DS and their caregivers. The family members of these children have to deal with many problems in managing these children. Therefore, health care authorities and social support organizations must provide them with more effective support (Gashmard, 2020).

Therefore, these parents suffer from a feeling of stigma towards themselves and society, and this stigma refers to a set of negative attitudes and beliefs that motivate the general public to fear, reject, avoid and discriminate against people with mental illnesses or behavioral disorders. Stigma leads parents of children with Down syndrome to avoid living, socializing or working. This leads to low self-esteem, isolation, and despair (Parker & Burke, 2007). This was indicated by the Al-Rayhanehs (2015) which aimed to reveal the level of social stigma prevalence and the level of family harmony among families of children with Down syndrome, as well as the Fulk (2014) study which aimed to determine whether the siblings of a person with Down syndrome find themselves stigmatized for their brother's injury. Sherrill (2012) study, which focused on the stigma felt by individuals with autism and Down syndrome and their parents and aimed at assessing participants' perceptions of children with autism and Down syndrome and their parents, and also the study of Hemat et al. (2010) which aimed to identify the specific sources of social stigma in families of children with Down syndrome,

In addition to the study Dehnavi et al. (2008) which aimed to identify the presence of stigma in parents of children with Down syndrome and the factors that are expected to influence stigma. Dinos et al. (2004) study also aimed to describe the relationship between the stigma resulting from mental illness and the psychiatric person and the treatment of self-stigma resulting from mental illness (Abdelall, 2021).

Atkinson et al. (1995) conducted a study to find out the relationship between the cognitive adaptation style (approach-avoidance) in mothers of children with Down syndrome and their emotional state and sensitivity. The study was conducted on the mother of their children with Down syndrome who were followed up for two whole years (Dabrowska & Pisula, 2010). And since measures of cognitive adaptation and emotional stress were used and applied, and sensitivity was measured by observing the child and mother, the results of the study showed that approaches and avoidance methods have been studied extensively under different names and that they are fixed over time, and that these cognitive adaptation variables may mediate psychological stress in my parents The disabled child in complex ways, and the results indicated that mothers who have strong tendencies to control stress reports have more emotional pressure than mothers who adopt the adaptive method with less ban and control, and at the same time the results showed that cognitive avoidance of stress and emotional stress reduces the mother’s behavioral sensitivity towards .her disabled child (Al-Arir, 2010)

3.2 Copying styles in parents of children with down syndrome

Disability is an unexpected thing. Every father and mother in the world is waiting for an ordinary child, let alone an ideal one. Therefore, it is not surprising that a child's disability represents a strong blow to hopes, and the strange thing is that parents accept their child's disability at once and without difficulties in the beginning. And since disability constitutes a real crisis, it causes psychological reactions that may be severe. What should be emphasized here is that such a thing is normal. There are those who say that it is healthy, but as long as the reactions are within certain limits (Al-Khatib, 2009).

The family is exposed to many different changes with the birth of a disabled child in it. Parents may experience shock, frustration, anxiety, depression, anger, feelings of guilt and shame as a reaction. Family relationships undergo many changes, either negatively or positively. The impact of the birth of a disabled child on the family is large, and this incident is likely to affect the survival of the family as a social unit as it was previously (Gashmard, 2020). The birth of a child with a severe disability may complicate the matter within the family, especially since this child has affected the parents' perceptions of themselves as parents as they wished. The irrefutable fact of the existence of a disabled child, which is the role that specialists in the field of family counseling for people with disabilities must play to overcome the psychological stages that constitute the reactions of parents, and a number of specialists have identified these stages, and among these stages is the stage of acceptance and coping that this research focused on (Al-Arir, 2010).

Research on dealing with families of children with developmental difficulties usually focuses on the specific burdens parents face rather than on individual differences in coping. Nevertheless, individuals may have distinct adaptation patterns or patterns. The concept of coping style was developed to describe individual factors related to differences in coping behavior (Dabrowska-Zimakowska & Pisula, 2010). Coping style is viewed as a propensity variable that indicates the relatively stable characteristics of an individual. Results from studies of different groups indicate that emotion-oriented coping style (e.g. engaging in self-blame rumination) is positively associated with health problems such as depression, anxiety, and physical disturbances, while task-oriented coping (an active problem-solving approach) -resolved) is negatively correlated with these conditions (Cohan et al., 2006).

The issue of individual differences in coping with stress in parents of children with developmental disabilities has not been investigated in detail. These differences may indicate adaptive behavior when dealing with stressors associated with raising a child with a disability. It would be interesting to see if there is a relationship between individual characteristics such as coping styles and parental stress level. This information will expand our knowledge about the relationship between personality factors and the severity of parental stress. Although, confrontation has an effect on the level of parental stress, the relationship between parental stress and conditioning has not been comprehensively explained. Some evidence suggests that specific coping strategies are among the factors that explain parental stress in both mothers and fathers of children with intellectual disabilities (Saloviita et al., 2003). Hastings et al. (2005) showed that adaptation to avoidance of activity is associated with a higher level of stress and mental health problems in both preschool-aged mothers and fathers and school-aged children. Smith et al. (2008) concluded that the well-being of mothers of affected young children was associated with a lower level of emotion-focused coping and a higher level of problem-focused coping, regardless of the child's level of symptoms. Some data also suggest that a higher level of parental stress is associated with religious conditioning. On the other hand, lower level stress is associated with seeking informal support (Hastings & Johnson 2001), dealing with problems (Lustig, 2002) and coping by focusing on family integration and cooperation (Jones & Bassey, 2005). Adaptation is facilitated by active coping patterns among mothers of affected children, while self-blame for disability is associated with poor adaptation. Nevertheless, these relationships were not confirmed in all studies. Higgins et al. (2005) found no relationship between coping strategies and parental coping. The results of some studies reveal some typical characteristics in the performance of parents of affected children. They were found to have a higher rate of social difficulties (e.g. poor friendships, isolation, shyness, poor family relationships, social phobia) (Murphy et al., 2000). They were also found to be more introverted than the normative sample (Dabrowska-Zimakowska & Pisula, 2010). In the study using the broad phenotype questionnaire, parents of affected children scored higher than controls on reclusive personality, rigid personality, and pragmatic language difficulties (Dabrowska-Zimakowska & Pisula, 2010).

Down syndrome is the most common genetic disorder of intellectual disability and one of the neurodevelopmental disorders caused by the addition of chromosome 21 (trisomy 21) in children (Davis, 2008). Children with Down syndrome have delays in motor development, language, specific verbal memory deficits, extensive cognitive defects, and they are at high risk of developing health problems such as congenital heart disease, shortness of breath, digestive disorders, hypothyroidism, and vision problems and Hearing Problems (Alexander & Walendzik, 2016). Risk factors for Down syndrome are aging during pregnancy related to the biological aging of the ovaries, having a history of having children with trisomy 21 before and environmental factors such as alcohol, nicotine, drugs (oral contraceptives, hormonal therapy, radiotherapy, fertility medications), exposure to toxic waste and infection (Stephanie Sherman, 2007). Slow growth in children with Down syndrome causes children with Down syndrome to need more care and attention (Alexander and Walendzik, 2016).

Stimulation is an important factor affecting the physical and mental development of children with Down syndrome, so parents of children with Down syndrome must take an active role in activities of daily living related to the self-care and health problems of children with Down syndrome.

Chronic health problems in children with Down syndrome affect different aspects of the lives of parents of children with Down syndrome and can lead to fatigue, social isolation, stress and caregiver burden (Bourke et al., 2009). In addition, it prompts parents of children with Down syndrome to change their daily habits and experience limited emotional, physical, and financial burdens in carrying out social and recreational activities, and to face the social consequences of societal stigma (Alexander and Walendzik, 2016).

Parents/caregivers allocate time caring for a child with Down syndrome an average of 40 hours per week, ranging from basic activities to medical support (Adelman et al., 2015). Caregiver burden is the stress or burden of parenting that occurs in a person caring for a disabled child. Burdens are divided into two parts, namely objective burdens and subjective burdens. Objective load refers to the extrusion and activities associated with negative addressing of caregivers. Personal burden refers to the feelings of caregivers that arise when performing the functions of caregivers. The concept of parenting burden by defining burden as the extent to which caregivers perceive the physical health, emotional health, social life, and financial status of parenting with a disability (Oh and me, 2009). Unfortunately, parents of children with Down syndrome do not receive enough social support from the community and do not like to admit they have children with Down syndrome for fear of criticism from society, causing higher rates of caregiver burden on parents/caregivers of children with Down syndrome (Alexander and Walendzik, 2016). Social support can be interpreted as care, values and guidance given to individuals by family, friends and other important people in their lives to provide physical comfort and emptiness. Social support is divided into five forms, namely: emotional support, award support, instrumental support, information support, and network support. Social support provided to parents/caregivers for Down syndrome can influence coping strategies and reduce stress to give positive outcomes (Alexander and Walendzik, 2016).

Coping is a practical method that can change over time and depends on how the choice of coping can vary according to the situation. In general, acclimatization is divided into reactive adaptation (reactions after stressors) and proactive adaptation (with the aim of neutralizing future stressors) (Schoenmakers et al., 2015). According to Lazarus and Folkman, coping is divided into problems - focused coping (PFC) and emotionally focused coping (EFC). Research conducted in Jordan suggests research with local sites, cultures, and more in analyzing coping strategies used by parents/caregivers of children with disabilities (LUKUT, 2021).

Some studies have reported that emotion-directed coping (that is, the tendency to respond to stress with self-directed emotional reactions, for example dysphoria) and avoidant coping styles are predictive of parental stress among parents of children with DS (Dabrowska & Pisula, 2010). Furthermore, other studies have found that parental coping style is closely related to parenting stress in mothers and caregivers of children with DS. On the other hand, it has been reported that parenting stresses can act as a mediator of differences in parenting patterns between mothers of children with DS and typically developing children (Phillips et al., 2017). Finally, the role of socioeconomic status (SES) should not be underestimated when considering factors associated with parental stress in DS. Indeed, families of young people with intellectual disabilities spend a significant amount of time providing care (Doran et al., 2012). In order to provide this care, many parents need to adjust the balance between work and family. Consistently, previous research has documented that parents of children with disabilities are more likely to be underpaid or have reduced working hours, due to their requirements to provide care for their children. Specifically, mothers of children with DS tend to work part-time more often than mothers of children with MS (Arora et al., 2020). Therefore, families of children with Down syndrome are at significantly increased risk of adverse socioeconomic conditions, with significant impacts on parental happiness, self-esteem, and self-sufficiency (Ewa, 2012).

4. Conclusion

This study highlighted the need to develop intervention and professional support programs to consistently provide these families with more support to enhance their health, reduce their stress, and improve their ability to cope with the problems of having children with DS. Family nurses, if available, can provide families with better and ongoing health education and counselling. They can also provide child-related education at home, implement regular family-centered home visits, and train families on how to deal with problems associated with DS. Educational interventions should also be undertaken to enable family nurses and other health care providers who currently work in health care settings to better respond to the challenging cases of families with children with DS. Furthermore, more rigorous studies should be conducted to assess the lives of caregivers and to improve home programs.

Research shows that the most commonly used coping strategy by parents/caregivers is emotion-based coping strategies. The social support parents/caregivers receive is moderate and has high levels of support. Describing the overall burden of a caregiver on parents/caregivers is most common at low and very low levels. There is no relationship between coping strategy and caregiver burden and no relationship between social support and caregiver burden.

This study is consistent with a large body of evidence indicating how exogenous problems are associated with higher levels of parental stress in DS; They also provide additional evidence to the current literature of the impact of comprehension problems and social communication defects on parents' stress levels, highlighting the importance of appropriate interventions for these aspects, as well as for improving family well-being in DS. Moreover, unemployed mothers showed significantly higher levels of stress than working mothers related to personal factors, such as life restrictions due to demands to raise children. This finding provides a useful indication for policy interventions aimed at improving the well-being of families of young people with DS.

Learning about the emotional burden and coping patterns of parents of children with Down syndrome will help find appropriate ways for parents/caregivers to adapt to children with disabilities. In addition to coping strategies, more research is needed on the social support needs of parents/caregivers that influence caregiver burdens. The large number of caregiver burdens on parents of children with mental disabilities makes researchers interested in knowing caregiver burden and its relationship to coping and social support strategies in parents/caregivers with Down syndrome so that the study results can be used to improve hospital services and help parents of a child with Down syndrome.

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