

Psychological Well-Being and Coping Strategies among Parents of Children with Down Syndrome

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Abstract

Down syndrome is a genetic disorder caused when abnormal cell division results in extra full or partial copy of chromosome 21. It is also known as trisomy 21. According to Economic Times Health (2021) report nearly 30,000-35,000 children born in India are affected by down syndrome. Children with Down syndrome develop at a slower rate than typically developing children. They require extra support and therapy to develop language, social skills, and motor skills. To support their child's development parents may need to engage in activities such as speech therapy, physical therapy, and occupational therapy. However, these therapies can be time consuming and expensive which can be challenging for parents to manage. Raising a child with Down syndrome is associated with higher level of parental stress, more symptoms of depression and anxiety, and poor psychological wellbeing than parents of typically developing children. Identifying the problems they experience in parenting a child with down syndrome and utilization of effective coping strategies make important contribution to improve psychological well-being. Coping strategies used by parents of children with down syndrome are problem-focused coping strategies, emotion focused coping strategies, active avoidance coping strategies and religious coping strategies which significantly improving the psychological well-being of parents of children with down syndrome.

Introduction

Down syndrome is a chromosomal abnormality where a person is born with an extra copy of chromosome 21. It is named after British physician John Langdon Down, who fully described the syndrome in 1866.

According to WHO (2017) report, Down syndrome is the most common chromosomal abnormality with an incidence of 1 in every 1000 to 1100 live births worldwide.

Physical Features of Down Syndrome

- ✓ Flat appearing face
- ✓ Small head
- ✓ Small mouth
- ✓ Upward slanting eyes
- ✓ Rounded cheeks
- ✓ Small and misshapen ears
- ✓ Weak and floppy muscles
- ✓ A malformed fifth finger

Complications of Down Syndrome



Heart Defects



Gastrointestinal Defects



Immune Disorders



Dementia



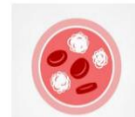
Sleep apnea



Obesity



Spinal Problems



Leukemia

Challenges of Raising a Child with Down Syndrome

➤ **Social Stigmatization:** Children with down syndrome may face social stigma and discrimination, which can affect their self-esteem and social development. Parents may also face judgment and negative attitudes from others. To address these social challenges, parents may need to advocate for their child's needs and work to educate others about down syndrome. They may also need to seek out supportive communities and resources, such as down syndrome support groups and community events which can be challenging for parents.

➤ **Medical Issues:** Children with down syndrome develop certain medical conditions such as heart defects, hearing loss, and vision problems. They may also be more susceptible to infections and other health issues. To address these medical issues, parents may need to engage in regular check-ups with a pediatrician or other healthcare provider. They may

also need to provide their child with additional medical care, such as surgeries or medication. This can be challenging for parents to manage both in terms of time and resources.

➤ **Developmental Delays:** Children with down syndrome develop at a slower rate than typically developing children. They require extra support and therapy to develop language, social skills, and motor skills. To support their child's development parents may need to engage in activities such as speech therapy, physical therapy, and occupational therapy. However, these therapies can be time consuming and expensive which can be challenging for parents to manage.

Psychological Well-Being of Parents of Children with Down Syndrome

- ❖ Parenting child with down syndrome can result in various psychological-emotional consequences including higher levels of parenting stress, anxiety and depression.
- ❖ Parents of children with down syndrome perceived more caregiving difficulties, child-related stress (distractibility, demandingness, unacceptability), and parent-related stress (incompetence, depression, health problems, role restriction).

Coping Strategies Used by Parents of Children with Down syndrome

- ❖ Coping refers to the conscious strategies used to manage internal and external stressful situation.
- ❖ The way individual cope with the problems plays a crucial role in their ability to adapt to stressful life circumstances and the use of coping strategies to manage stress and problems has a significant impact on psychological wellbeing.
- ❖ Coping strategies used by parents of children with down syndrome are problem-focused coping strategies, emotion focused coping strategies, active avoidance coping strategies and religious coping strategies.
- **Problem-focused coping strategies:** Problem-Focused Coping is a psychological coping

strategy that aims to deal with stressors by directly confronting and resolving the root cause of the problem or reducing its impact. It involves actively seeking solutions, gathering information and making efforts to change the stressful situation.

- **Emotion focused coping strategies:** Emotion-focused coping refers to strategies to manage stress that involve emotional regulation.
- **Active avoidance coping strategies:** Active avoidance coping refers to a deliberate and conscious effort to escape or prevent situations, experiences or stimuli that are perceived as threatening, unpleasant, or anxiety-provoking.
- **Religious coping strategies:** Religious coping strategies often stem directly from an individual's religious beliefs system and help them to construct meaning and form interpretations (both positive and negative) of stressful situations and events.

Conclusion

Parents of children with down syndrome perceived more caregiving difficulties in children's health, handling and feeding than parents of typically developing children. Parents may experience a range of emotions including grief, guilt, anxiety, and sadness due to unpredictability of their child's condition. They also feel isolated from friends and family who do not fully understand their situation and problems which lead to a sense of loneliness. Dealing with healthcare, education and social services systems can be complex and frustrating for parents of children with down syndrome. To mitigate these stresses, parents can seek support from various sources such as support groups, professional help, education and advocacy, respite care and financial assistance. Determining the stress levels and problems they experience in parenting a child with down syndrome and utilization of effective coping strategies such as problem focused coping strategies will make important contribution to improve psychological well-being of parents of children with down syndrome.

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