

بسم الله الرحمن الرحيم



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شبكة المعلومات الجامعية التوثيق الالكتروني والميكرو فيلم



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جامعة عين شمس

التوثيق الإلكتروني والميكروفيلم

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Mother's Coping among Primary School Child with Down Syndrome

Thesis

*Submitted for Partial Fulfillment of Master Degree
in Community Health Nursing*

By

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(B.Sc. In Nursing)

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Ain Shams University

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List of Abbreviations

<i>Abb.</i>	<i>Meaning</i>
CVS	: Chorionic villus sampling
DS	: Down syndrome
GERD	: Gastroesophageal reflux disease
HCG	: Human chorionic gonadotropin
HD	: Hirschprung disease
ID	: Intellectual disability
IDEA	: Individuals with Disabilities Education Act
IQ	: Intelligence Quotient
MR	: Mental retardation
MSS	: Maternal serum screen
NIPT	: Non-invasive prenatal testing
OSAS	: Obstructive sleep apnea
RN	: Registered nurse
PAPP-A	: Pregnancy-associated plasma protein-A
TSH	: Thyroid stimulating hormone
WHO	: World health organization

Mother's coping among primary school child with Down syndrome

Abstract

Background Down syndrome (DS) or Down's syndrome, also known as trisomy 21, is a genetic disorder caused by the presence of all or part of a third copy of chromosome 21. When mothers of DS children experience stress, they use certain strategies to cope with this stress to regulate their emotions. **Aim of this study:** to assess mother's coping among primary school child with DS. **Design:** Descriptive study design was used. **Setting:** The study was conducted at three special needs schools (ALTarbiH ELfikria) at Fayoum governorate. **Sample:** A purposive sample was used, they were 95 mothers, and their children. **Tools:** First tool structured interviewing questionnaire, to assess characteristics of mothers, children, history of DS child, and to assess mother's knowledge about DS. Second tool: physical examination sheet for DS children. Third tool: mothers' coping scale. Fourth tool: mothers' needs scale. **Results:** The study results showed that, three fifths of mothers had negative coping patterns, in which more than two fifths of them never able to cope with their children disability also, study results reported that the economic needs were most important needs for mothers. **Conclusion:** More than two-thirds of mothers had unsatisfactory knowledge regarding of Down syndrome. Religious and doctrinal coping was the most coping strategy used by mothers, in which more than half of mothers were always able to cope religiously. **Recommendation:** Provide educational program to parents of children with DS and encourage mothers and fathers to participate in mentoring programs and receive rehabilitation services for their children.

Keywords: Down syndrome, Mother's coping, primary school child, mothers' needs for caring of child with DS.

Introduction

Down syndrome (DS) or Down's syndrome, also known as trisomy 21, is a genetic disorder caused by the presence of all or part of a third copy of chromosome 21. It is usually associated with physical growth delays, mild to moderate intellectual disability, and characteristic facial features. The average IQ of a young adult with Down syndrome is 50, equivalent to the mental ability of an 8- or 9-year-old child, but this can vary widely (**Munny, 2019**).

The prevalence of DS is 1 in every 700 babies born in the world. Its estimated incidence is 1 per 1000 live births. Annually, 3000 to 5000 children across the world are born with DS. Children with DS exhibit persistent intellectual, developmental, and health issues that require medical and rehabilitation services, both of which can impact family systems (**Gashmard et al., 2020**).

Down syndrome can cause a number of medical complications. Some of these complications are more serious than others, but most of them can be treated. The most serious complications of DS include heart defects, blood disorders that can include leukemia (cancer of the blood),

hormonal disorders, skeletal problems and immune system problems (**Ostermaier, 2019**).

Besides deficits in cognitive and social areas, children DS often have other comorbid chronic health conditions, such as congenital heart defects, gastrointestinal disease, hypothyroidism, respiratory disorders, ophthalmologic problems, and hearing problems, which make extra-care and extra-attention necessary and may be an additional source for parents' worries and fears. As a result, on the one hand, families of these children have to spend much energy and patience in managing the child's behavioral, emotional and health problems (**Kazemi & Kheirollahi, 2016**).

On the other hand, parents (specially mothers) of children with DS face different challenges arising from necessity of dealing with social consequences of the illness like potential threat of stigmatization. Intra-psychic, they may undergo a painful process in losing the imagination of having a "normal" child and to accepting that their child is "different". On being told their newborn baby has impairment, parents tend to react with a mixture of shock and disbelief, followed by denial (**Zappella, 2016**).

Generally, mothers of children with DS are having plenty of problems in their life in physical, psychological and social compared to the mothers of normal children. Mothers of children with intellectual and developmental disabilities as DS are facing lots of negative emotions like stress, anxiety, depression and they also have more fear about their future and their child's future which will have adverse effect on the wellbeing due to inability to cope with this situation. Some mothers complained about the decline in the quality of their marriages. Depression and declining quality of parental marriages then cause difficulties in their work and career. In spite of that some parents accept the reality and tend to lead a positive life it developing their coping skills and self-esteem **(Parameswari & Eljo, 2016).**

Coping strategies can be defined as cognitive efforts or ongoing behavioral efforts to overcome the problem of feeling disappointed or hopeless because they are unable to meet internal or external demands due to limitations. Alternatively, it can be simplified as a process consisting of cognitive effort and behavior to regulate psychological stress. Coping is an active effort to control, reduce, or tolerate stress demands, so that coping is always related to decision making about actions to be taken by someone to deal with stress faced **(Gashmard et al., 2020).**
