

Burden and Stressors among Caregivers of Children with Down Syndrome

Thesis

Submitted for Partial Fulfillment of the Requirements
for the Master Degree in

(Psychiatric Mental Health Nursing)

Submitted by

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بِسْمِ اللَّهِ الرَّحْمَنِ الرَّحِيمِ

قالوا

لسبحانك لا علم لنا
إلا ما علمتنا إنك أنت
العليم العظيم

صدق الله العظيم

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List of Abbreviations

<i>Abbrev.</i>	<i>Full-term</i>
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- DS** : Down Syndrome
- ID** : Intellectual disabilities
- NT** : Nuchal translucency

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Abstract

Down Syndrome is the most common cause of mental retardation and malformation in new born. It occurs because of the presence an extra chromosome. **The aim** is to assess burden and stressors among caregivers of children with Down Syndrome. **Research design:** A descriptive study design was done. **Setting:** The study was conducted in school of intellectual Education in Kafr-Elsheikh city which provide educational and rehabilitation services to 40 Down Syndrome children. **Sample:** Purposive sample was selected which include (40) parents providing care for their children of Down Syndrome. **Tools:** Interviewing questionnaire tool for caregivers and child were used which included four parts: (1) Socio-demographic characteristics of the caregivers and their children, (2) Health condition and medical history of the child, (3) Questions related to child behavior of daily living activities (4) caregiver Burden scale. **Results:** The study results found that more than half of caregivers were suffering from physical, psychological, social and the majority suffering from financial burden as a result of caring for their child. **Conclusion:** Based on study findings, it was concluded that there was a significant relation between previous hospital admission and burden among their caregivers, there is no significant relation between child behavior of daily life activities of Down Syndrome children and burden among their caregivers. **Recommendation:** Apply and implement home health education by all health services units to provide the caregiver with sufficient information about Down Syndrome, collaboration between Ministry of Health and Population and Ministry of Social Affairs to help and support families with Down Syndrome child through saving money, drugs, and home health care facilities aids.

Keywords: Down Syndrome, Caregivers, Burden.

Introduction

Down Syndrome constitutes a major public health problem all over the world. It refers to an intellectual deficit causing incompetence in the performance of social roles (*Bull et al., 2011*).

Down Syndrome (DS) is a relatively common congenital birth outcome resulting from chromosome 21 abnormality. It is the most common chromosomal cause of intellectual disabilities (ID) with an incidence of 1 for every 800 to 1000 live births. The incidence would be more if spontaneous abortions at first and second trimester are account (*Wiseman, F. K., Al-Janabi, T., Hardy, J., Karmiloff-Smith, A., Nizetic, D., Tybulewicz, 2015*).

The caring of Down Syndrome child within a family is one of the major stressors facing family caregivers that result from uncertainty regarding to meet physical, social, emotional & cognitive alteration of a child. In addition to siblings often fill resentment, insecurity and fear of being affected of a similar condition (*Cohen WI, 2009*).

Caregiver burden is defined as “a multidimensional response to physical, Psychological, emotional, social and financial stressors usually associated with the experience of caring (*Adelman, Tmanova, Delgado, Dion, & Lachs, 2014*).

Caregiver stress is the emotional and physical strain of caregiving. It can take many forms. For instance, caregivers may feel frustrated and angry taking care of someone with

Down Syndrome who often wanders away or becomes easily upset, guilty because caregivers think that they should be able to provide better care, despite all the other things that you have to do, lonely because all the time you spend caregiving has hurt your social life (*Granek, L., Rosenberg-Yunger, Z., Dix, D., Klaassen, R., Sung, L., Cairney, J., & Klassen, A (2014).*

Stress is the hallmark of caregiving and has both primary and secondary pathways to the adverse effects of caregiving. Primary stressors are those objective, observable activities of caregiving that might surface from the caregiving tasks necessary for assuring the safety and care of the care recipient (*Wilborn-Lee, 2015).*

Secondary stressors are the intangible strains and stresses that occur in the caregiving role and affect the caregiver's emotional and psychological well-being. Secondary stress might occur if conflict arises between the caregiver and a family member regarding the quality of care the primary caregiver provided to the care recipient (*Wilborn-Lee, B (2015).*

The nurse plays an important role in helping the family to relieve burden and stressors. The mental health nurse helps families to understand social and psychological needs to gain insight about adjustment and coping patterns with their Down Syndrome children through providing information for family members to understand their needs, problems and care of child with Down Syndrome (*Cunningham, 2010).*

Significance of the Study

Down Syndrome occur in about one in every 800 -1000 live births. It affects an equal number of boys and girls. It affects 1% to 3% of the population in developed countries. It is estimated that one in every 800-1000 live births will result in a child Down Syndrome, representing approximately 35000 individuals with Down Syndrome in the USA today (*Wiseman et al., 2015*).

In Egypt, the incidence of Down Syndrome has been 1 per 1000 live births reported by (*Elsayed, Elsayed, & Ezz-Elarab, 2014*).



Aim of the Study

The aim of this study was to assess burden and stressors among caregivers of children with Down Syndrome

Research Question:-

1. What are burden and stressors among caregivers of children with Down Syndrome?
2. Does burden and stressors among caregivers affect their ability of caring?