



شبكة المعلومات الجامعية
التوثيق الإلكتروني والميكروفيلم

بسم الله الرحمن الرحيم



MONA MAGHRABY



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شبكة المعلومات الجامعية التوثيق الإلكتروني والميكروفيلم



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جامعة عين شمس

التوثيق الإلكتروني والميكروفيلم

قسم

نقسم بالله العظيم أن المادة التي تم توثيقها وتسجيلها
علي هذه الأقراص المدمجة قد أعدت دون أية تغيرات



يجب أن

تحفظ هذه الأقراص المدمجة بعيدا عن الغبار



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Perception and Experiences of Family Caregivers having Children with Mental retardation

Thesis

*Submitted for Partial Fulfillment of the Requirement of
Master Degree in Nursing Science
(Psychiatric / Mental Health Nursing)*

By

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*Faculty of Nursing
Ain Shams University
2021*

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giving me the power to perform and
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Rasha Elsayed Ali

Dedication

This work is dedicated to:

*To the **soul of my father** who was the first teacher in my life, to the symbol of love, **My Mother**, who always inundates me with mercy and care and pray for my parents, to them lovely **sons (Habeba-Hana-Abrar)** and my **Husband** they always supports my ambitions and lights my road all the time. They were so patient and have created for me an ideal atmosphere to enjoy my work, I have enjoyed it. I also dedicate this to **my sister** who always provides me with their continuing love. A special – Thank you- to **Mr. Khaled Gbr** who share in this work for their great support and pushing me forward in every step in my life.*

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List of Abbreviations

Abbr.	Full-term
ADL	Activity Daily Living
DD	Developmental Delay
ID	Intellectual Disability
IQ	Intelligence Quotient
MR	Mental Retardation

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Abstract

Background: Mental retardation (MR) is one of the most prevalent developmental disabilities. Care for children with mental retardation had to make great changes in their arrangement and expectation for their child, also they had to change their life style for meeting the mentally retarded child's need. **Aim:** this study aimed to assess the perception and experience of family caregivers having children with mental retardation. **Design:** A descriptive design was utilized in this study. **Setting:** The study was carried out in the School of El-tarbia El-fekrya affiliated to Ministry of Education which located at Sharkia governorate. **Subjects:** The study was conducted on included 100 family caregivers of children with MR who agreed to participate in the study **Tools of data collection:** Socio-demographic Sheet, Level of dependence scale, Parental Perception Questionnaire, Questionnaire to assess family experience for children with mental retardation. **Results:** The highest percentage of caregivers were female and more than two third of children with mental retardation were male, the most of caregiver having child with mental retardation had positive perception, and regarding to experiences were correction child behavior, there was non-significant relation between experiences of caregivers and their perception, there is a statistically significant relations between educational level of family caregivers and their experiences. while is no statistically significant relations between age, sex and marital status of family caregivers and their experiences and perception, **Conclusion:** The present study concluded that the majority of family caregivers were correct to their child's behavior as well as have positive & negative perception toward child with mental retardation **Recommendations:** Future research to assess factors that may influence role of caregiving and different challenges faced by family caregivers in rearing different aged children with Mental retardation.

Key words: Mental retardation, perception and experiences of caregiver.

Introduction

Mental retardation is a condition of developmental deficit, starting in childhood, which leads to significant limitation of cognition or intellect and poor adaptive functioning in their daily life (**Ramasubramanian, Chellamuthu, Selvikumari, Pandian, Gopi, 2019**).

Family Care givers of individual with intellectual disability experience numerous situations in their daily routine. They experience emotional, physical and financial challenges that reflected as burden of care (**Upendra Singh, Singh, 2020**).

Children with mental retardation require intensive care by parents to optimize their developmental stages such as conducting medical examinations, counseling, and training. Old parents and other family members are the most important part for children with mental retardation to be able to live their lives (**Endriyani, Yunike Yunike, 2017**).

So that Parents' perceptions have the possibility to influence their recognition of the problem, their help-seeking behavior, and their engagement and adherence with treatment (**Mubarek Abera, Jeffrey M. Robbins & Markos Tesfaye, 2016**).

Previous Studies have traditionally analyzed the possible negative impact of having a child with disabilities on parents, and have sought to identify the aspects that may generate negative

perceptions and high levels of stress; however, other studies have found that having a child with mental retardation can lead parents to perceive certain aspects of family life positively (**Ferrer, Vilaseca, Gua`rdia, Olmos, 2017**).

Vilaseca, Ferrer, Gua`rdia and Olmos, (2014), confirmed that parents of children with mental retardation presented both positive and negative perceptions. Certainly, positive, and negative perceptions came to be considered as independent concepts.

Karmanshahi, Vanaki, Ahmadi, Kazemnezad, Mordoe and Azadfalah, (2008), explained family perception about mental retardation found six major themes: challenging the process of acceptance, painful emotional reactions, the interrelatedness of mother's health and child's wellbeing, struggles to deal with oneself or the child, inadequate support from the family and the community, and the anxiety related to child's uncertain future.

Nurses spend a long period of time in caring of mental retardation children and with their caregivers. Therefore, nurses should facilitate and encourage open communication about caregiver needs, feelings and concerns related to child care; also they teach caregivers how to care factors that will mediate a positive adjustment and outcome (**Norton, Dyches, Harper, Roper & Caldarella, 2016**).