Barriers Confronting Parents Caring of Children with Intellectual Disabilities: A Descriptive Study

Thesis

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

By

Gehad Fawzy Mohammed Ibrahim

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Supervised by

Prof. Dr. Safy Salah Eldin AlRafay

Professor and Head of Pediatric Nursing Department

Faculty of Nursing-Ain Shams University

Dr. Fatma Mohammed Mohammed

Lecturer of Pediatric Nursing

Faculty of Nursing – Ain Shams University

Faculty of Nursing
Ain Shams University
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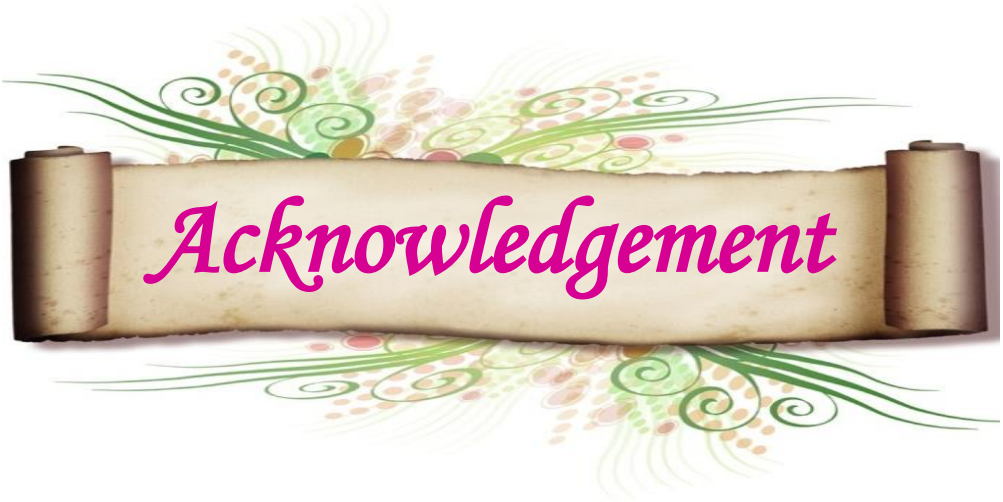

Praise to "Allah", the Most Gracious and the Most Merciful Who Guides Us to the Right Way.

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List of Abbreviations

AIDS	**:** Acquired Immunodeficiency Syndrome
AAIDD	**:** American Association of Intellectual and Developmental Disabilities
APA	**:** American Psychiatric Association
DSM	**:** Diagnostic and Statistical Manual of Mental Disorder
ICF	**:** International Classification of Functioning
ID	**:** Intellectual Disability
IQ	**:** Intellectual Quotation
IUGR	**:** Intrauterine Growth Retardation
PKU	**:** Phenylketonuria
RH	**:** Rhesus factor
UNICEF	**:** United Nations Children Emergency Fund
WHO	**:** World Health Organization

Abstract

Background: Intellectual disabilities is the most common disabilities in children and young adults which significantly refers to subaverage general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested during the developmental period. **Aim**: The study aims to assess barriers confronting parents caring of children with intellectual disabilities. **Design**: A descriptive exploratory study. **Sampling**: A purposive sample comprised of 150 parents of children with intellectual disabilities. **Setting**: This study was conducted at Itay Elbarood School for children with Intellectual Disabilities affiliated to Damanhour University at Elbehera governrate. **Tools of data collection**: included 2 tools: Interviewing Questionnaire to assess needs and knowledge of parents about intellectual disability and Likert Scale to assess parents' attitude regarding abilities in facing barriers to successful parenting during perform daily activities. **Results**: This study revealed that the mean age of studied parents was 32.26±4.2, and majority of them had unsatisfactory knowledge about intellectual disabilities and high total needs level, and most of them had medium attitude toward caring level. **Conclusion**: the current study concluded that families living with intellectual disability children have physical, social, psychological and emotional barriers that confronting parents caring of children with intellectual disabilities. In addition, many factors such as child sex, age, birth order had a role in shaping the parents knowledge and caring level of children with intellectual disability. **Recommendations**: The study recommended that pediatric rehabilitation units should be established for supporting, exchanging experiences and advices among parents and families of children with intellectual disabilities.

Key words: Children, parents, Intellectual Disability, Barriers.

Operational Definitions

Intellectual disability:

Intellectual disability is a disability characterized by significant limitations in both intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills. This disability originates before the age of 18 years **(American Psychiatric Association (APA), 2013).**

Intellectual functions:

Intellectual functioning is mental abilities or "intelligence." That refers to the ability to reason, plan, think, and communicate. These abilities allow us to solve problems, to learn, and to use good judgment **(Francoeur et al., 2010).**

Adaptive behavior:

Refers to behavior that enables a person to get along in the environment with greatest success and least conflict with others. Adaptive behavior relates to every day skills or tasks that the "average" person is able to complete life skills **(American Psychiatric Association (APA), 2013).**

Down syndrome:

Down syndrome 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 **(Dabrowska & Pisula, 2010).**

Autism:

Autism is a neuropsychiatric disorder characterized by severe and sustained impairment in social interaction, deviance in communication, and patterns of behavior and interest that are restricted, stereotyped, or both. Onset is generally before age 3 years **(Abirami et al., 2018).**

Cerebral palsy:

While Cerebral Palsy is a blanket term commonly referred to as "CP" and described by loss or impairment of motor function, Cerebral Palsy is actually caused by brain damage by brain injury or abnormal development of the brain that occurs while a child's brain is still developing before birth, during birth, or immediately after birth **(Brossard-Racine et al., 2012).**

Introduction

Intellectual disability (ID) as a developmental condition is characterized by significant deficits in both intellectual functioning and adaptive behavior, including conceptual, social and practical skills **(American Psychiatric Association (APA), 2013).**

Intellectual disability has a great effect on child and family, when disabled children lack independence, child may experience depression and social isolation as a result of their limitations. They may require additional assistance at school or at home; the level of assistance they need will depend on the child case and the severity of the disability. Children with intellectual disabilities may feel frustrated because they may not be able to communicate and portray what they are feeling, they find difficulty in finding suitable activities and they can't learn new information as quickly as other children **(Krahn et al., 2009).**

Living with a disabled child can have profound effects on parents, siblings, and extended family members. It affect all aspects of family functioning. On the positive side, it increase family members' awareness of their inner strength, enhance family cohesion, and encourage connections to community groups or religious institutions. On the negative side, the time and financial costs,

physical and emotional demands, increase stress, affect mental and physical health, make it difficult to find appropriate and affordable child care, and affect decisions about work, education and having additional children. It may be associated with guilt, blame, or reduced self-esteem **(Scott & Havercamp, 2016).**

Some children may require only occasional help and guidance with certain cognitive functions where others may require more extensive assistance or even full-time attention. The seriousness of the disability may also vary. A special needs nurses will often have to interact with the family of intellectual disabled children in order to teach them the skills necessary to take care of and interact with their child. In addition, a special need nurse should has an excellent communication skills to communicate with child and the family according to different developmental stages in certain cases **(Taua et al., 2012).**

Children with intellectual disabilities require much parental attention. Several researchers have focused on barriers facing parents for caring of children with intellectual disabilities. These barriers are psychological, emotional, social, and economic. Psychological and emotional challenges included being stressed by caring tasks and having worries about the present and future life of their children. They had feelings of sadness, and inner pain or bitterness due to the disturbing behavior of the children. They

also experienced some communication problems with their children due to their inability to talk, social challenges are inadequate social services for their children, stigma, burden of caring task, lack of public awareness of mental illness, lack of social support, and problems with social life. The economic challenges are poverty, child care interfering with various income generating activities in the family, and extra expenses associated with the child's illness **(Heller, 2016).**

Significance of the study:

According to the **Ministry of Health and Population, 2015** it was found that less than one percent of children age 0-9 years have any disability limiting their ability to carry out daily activities. The types of disabilities or conditions these children had included autism or other mental conditions (40%), motor problems (28%), speech disabilities (32%), auditory problems (9%), and vision issues (8%)

According to the **WHO report of disability and Global Burden of Disease 2011** estimates that 15.3% of the world population had "moderate disability", while 2.9% experienced "severe disability". Among those aged 0 –14 years.

Intellectual disability is one of the most common developmental disability. In Egypt, prevalence of childhood disability was estimated to be about 8.0%, there are about 2.5

million children aged less than 18 years with one or more physical or mental disabilities **(Durkin, 2002).**

Children with intellectual disabilities have a greater risk of experiencing physical, social, psychological and emotional problems. Parents of intellectual disabled children have a lot of unmet needs as health developmental need, care need, educational need, financial need and service participation need. So that this study would be of great value for assessing barriers confronting parents caring of children with intellectual disabilities.