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ISSN (Online) : 2455 - 3662
SJIF Impact Factor :4.924

EPRA International Journal of Multidisciplinary Research

Monthly Peer Reviewed & Indexed
International Online Journal

Volume: 4 Issue:10 October 2018



Published By :
EPRA Journals

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**EPRA International Journal of
Multidisciplinary Research (IJMR)**

CARER EXPERIENCE WITH CHILDREN WITH DOWN SYNDROME

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ABSTRACT

This paper explores the experiences and coping approaches of Down syndrome carers resulting from in-depth interviews among five families with children with Down syndrome in Kuala Terengganu. The purpose of the interviews was to examine family carers' experiences and get in touch with the child. The paper specifically focuses on the issues of tolerance, sacrifice and attention in handling such children and coping with adaptation to the role of carer. The findings reveal that for the majority of family carers, their experience was one of constant searching for support and information. The anxiety and frustration associated with unpredictable and irregular support and a lack of information were major sources of concern for the carers in the study. However, carers were found to use a number of positive and negative coping approaches to deal with the pressure associated with their caregiving role. The study also concluded that the benefits of knowing a person with Down syndrome may extend beyond the immediate family members and into the community.

KEYWORDS: *Carer experiences and Down syndrome child.*

INTRODUCTION

Every family has their joys, stresses, and challenges, but when you have a child with Down syndrome, things look a little different. Down syndrome is a genetic disorder causing various intellectual and physical developmental problems. The characteristic of life of families managing for children with Down syndrome is unclear in Malaysia. Speak of Down syndrome in Saudi Arabia, most primary caregivers tend to be women (mothers) in term of caring practices and experience

(Sijeeni & Barnard, 2018). The absence of knowledge and practices regarding families' support in caring for children with Down syndrome inspired the researcher to look into this issue. In this research we have seen different understanding of experiences in caring for their children with Down syndrome. The viewpoints of families with disabilities are necessary for improving knowledge and practices to support them.

According to Farrasbiyan (2009), some children with Down syndrome are able to develop like

normal children but more slowly. This group with Down Syndrome facing disabilities or deficiencies in terms of cognitive, effective and psychomotor skills. Kumin (2003), revealed that these children are explained to have their own thinking and developmental differences compared with normal children. Down syndrome children have a problem of thinking that is retarded intellect at either a little or moderate level. It is estimated that children with Down syndrome have a low level of intelligent quotient (Zuriahwati, 2012). This explains, they have a low level of thought and require special guidance to learn something new in their life. Initially, most families with children with Down syndrome will experience emotional disturbances and conflict, which if not properly managed will lead to serious distress. Families with this experience should be assisted in terms of physical, mental and financial support either from family and community. This will make it easier to help families with children with Down syndrome in all things. For example, they may have lost confidence in dealing with society and experience the problems of less fortunate families. Hence, support provided by outsiders can help family members cope with the situation and give the public an understanding of children with Down syndrome. Early life experiences in family are important and can affect the behavioural pattern of children. The family is a comprehensive structure consisting of interdependent elements and influencing the overall family function. Children with disabilities not only require love from family members but more importantly care and protection such as physical, emotional and psychosocial support. Down syndrome children usually have very limited abilities and are always isolated from their environment. Therefore, families play a vital role in supporting their potential to live in society.

OBJECTIVE

The aim of this study was to explore the experiences of families with children with Down syndrome in one of the area in Kuala Terengganu.

METHODOLOGY

In this study, a qualitative method was applied. The research explores the lives of carers with Down syndrome children. Creswell (2010), mentioned that qualitative research is a method for exposing and understanding the meaning of a number of individuals considered to be derived from the social issues of the study. A purposeful sampling system was used to recruit parent participants (Bogdan & Biklen, 2003). A research statement leaflet was distributed by the teachers from Down syndrome day care centre (which covered four villages in Kuala Terengganu – not to reveal the specific area due to sensitive issue). Potential participants called the researcher for more information

about the study. The researchers selected five parents with children with Down syndrome and ages ranging from 10 to 15 years. The researchers chose the criteria based on the age of the child to explore and understand family caring ability in the age range mentioned earlier. Furthermore, the process of development and learning with parental guidance are important within these ages. The data were collected during in-depth interviews face-to-face with the guardian, commonly at the family's home. Interviews lasted between 20 and 30 minutes. The interview schedule was developed by the researcher and modifications were made after obtaining comments from professionals in the field. It consisted of four open-ended uncomplicated questions derived from the literature and covered data on socio-demographic characteristics, how and to what degree family members were affected, and attitudes towards the child with Down syndrome. The tape recordings of the interviews were transliterated straightaway following the interviews, entered into the computer program and explored to identify themes.

RESULTS

Thematic analysis is a way to identify the themes contained in a phenomenon. There are three themes that have been obtained by a researcher on the ability of a family to care for Down syndrome. The ability of this family to be identified based on the thematic analysis that depends on the objective of the study. All of them have experience of different kinds of raising children with Down syndrome. Three sub-themes were extracted from the interviews: 1) Attention, 2) Family acceptance, and 3) Family knowledge.

Attention

Among the factors that affect the physical and mental development of the child, the most important is stimulation from close contact between mother and child. This becomes extremely relevant when dealing with children with Down syndrome, who develop slower and therefore need to dedicate themselves significantly to foster their development. These children require increased stimulus and attention in their daily activities. Such level of care on the part of parents of children with Down syndrome alters daily routines. Thus, functional, structural and emotional changes occur in all family members, particularly in parents' relative to their quality of life (Buzatto & Beresin, 2008).

Family Acceptance

Mothers must go through a grieving process before they are able to accept their disabled child. In this stage, mothers were trying their best to hide shame from outsiders to maintain face. Therefore, their coping resources were very limited. Usually, the husband was the only who one could provide support. Coping

strategies were emotion-focused and avoidance was particularly evident. Whether or not the mothers had accepted their children, family caregiving and child rearing remained their major duties. Even though they were extremely upset, they still had to shoulder all the responsibilities of caring for a child with special needs (Beckman, 1991).

Family Knowledge

This section discusses how mothers perceive their parenting role in relation to their child and the practices in which they engage to support their child's learning and development. There was awareness by all the mothers of the importance of optimal learning experiences of their child to achieve potential, as well as recognition that a major goal in parenting is to ensure that the child can become independent, irrespective of any intellectual disability. Families deal with formal services, and the mother's experiences are often primarily with health care services. A mother's experience with professionals may include health care workers in the hospital who did not handle her situation sensitively enough (Cunningham, 1996).

DISCUSSION

The need for special attention requires that parents involve themselves in every activity and care of their child with Down syndrome. The increased responsibility and workload that these parents have in caring for children with Down syndrome. This level of involvement in the care and in the activities of such children requires more time from parents. In caring for a child with developmental problems, parents will be able to change possibly negative issues into gains, notwithstanding their difficulties. They learn to know their children better and to notice their children's abilities, bringing them feelings of joy.

In addition, parents play a significant support role in this shift in attitudes as they sought to increase the social and educational opportunities available to their children. Exploring parental experiences provides knowledge about family strengths and resources, as well as the needs of families that could enhance their quality of life. Higher expectations of the capabilities of children with intellectual disabilities have led to significant gains in their demonstrated educational achievements and provided them with more opportunities to participate in society.

Mothers care very much about the attitude of other people towards themselves and their children. This is related to the cultural stigma of giving birth to a mentally handicapped child. Demonstrating positive attitudes and avoiding discriminative behaviour on the part of professionals is a step forward in facilitating public acceptance. Informing mothers about ways of handling the public's possible negative responses will enable them to cope more confidently. Therefore, to

help the child integrate into society, government and nurses should educate the public that people with mental retardation are not infectious, seldom display violent behaviour, and are not to be feared or spurned. These reactions all involve community-based rehabilitation.

CONCLUSION

This small research indicates that families of children with Down syndrome in the area in Kuala Terengganu as elsewhere experience substantial social and emotional struggles. The children themselves encounter difficulties with their daily lifespans and in their time to come. Parents of these children do their finest to pay attention of them with love and generosity. It is important that the difficulties of children with Down syndrome and of their families become better comprehended and acknowledged in society.

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