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Challenges and difficulties facing families of people with special needs, Taif city, KSA: A qualitative study

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'Disability' is a broad term that refers to a wide range of impairments, activity restrictions, and participation limitations. A significant reduction in the ability to comprehend new or complex information, as well as the ability to learn and apply new skills or abilities, is defined as intellectual or mental disability by the World Health Organization (WHO) in 2015. The aim of this paper explores the challenges and difficulties faced by the families of the children with special needs in Taif city, Kingdom of Saudi Arabia. A qualitative study design with interview was employed to explore which challenges and difficulties the families experienced, from March 2022 to April 2022. study used thematic analysis method. A total of **12** families caring for children with different special needs were interviewed two themes emerged from the data. From the families' point of view, Challenges faced by children with special needs and the challenges faced by the families of children. A group of society has a view indicating that the disabled person has a deficiency, and this may lead them to ridiculous or surprising, as if the society does not believe in the abilities of this group or its capabilities to lead a normal life. Families also suffer financially because of the costs they face, which include the costs of obtaining the best health services.

Keywords: Challenges, difficulties, Families, special needs

INTRODUCTION

The World Health Organization (WHO, 2022) estimated over one billion of the global population suffers from a disability. The General Authority for Statistics of Saudi Arabia (2022) published that 2.9% of Saudi population is dealing with extreme disabilities. Furthermore, the Equality Act 2010, defines disabilities as the encounter between health condition and its impact on the individual's environment and personal life (GOV.UK., 2022). Children with disabilities find it difficult to comprehend new or complex information. Thus, they mostly depend on their parents survive. According to studies, family caregivers of children with disabilities have both positive and negative experience (Rose et al. 2022). The experience varies according to the child's disability, and characteristics. However, it is evident that negative experience far passes the positive experience on family caregivers (Schulz et al. 2020). This is caused by the social, economic, and psychological stress in providing care (Al-Salloum, 2020). There are many psychological stresses on family caregivers, for example

the pressure could arise from the greater health needs and the higher risks of developing secondary health conditions (Bright et al. 2018). Furthermore, the economic stresses develop from the need to cover all the health expenses needed for their children with disabilities. hence, it is essential to build in a new policies and procedures to decrease those stresses on family caregivers.

The United national Platform (2022) in Saudi Arabia emphasizes the importance of the legal framework related to the fundamental law of authority, safeguarding from harm, social care, therapy center and health care equality in education for people disabilities. Therefore, in Saudi Arabia, the home-medicine services for beneficiaries includes psychological and social support alongside educating the individuals and their families about their conditions (Ministry of Health, 2022). It is important to support the families socially, financially, physically, and mentally. According to sharika (2022), the families' necessities differ depending on the other types and severities of disabilities. However, most

families acquire social support such as interacting with other families who also have members with disabilities. Furthermore, the existence of care home and care centers majorly contributes to physically support individuals with disabilities and their families. Also, the Saudi government financially aid citizens with disabilities through services such as the financial subsidy service for people with disability (Unites National Platform, 2021). On the other hand, the mentality of families with disabilities is usually left unobserved (Graaf et al. 2022). Hence, the lack of mental support for families with disabilities. In addition, there is a general lack of studies in the Kingdom of Saudi Arabia on the issue of parents of disabled individuals and the challenges they face, which could lead to demotivating change and enhancement of the quality of life those individuals deserve. Therefore, it is fundamental to start expanding the research on this subject to benefit the society in general and specifically, the families of people with disabilities. .

MATERIALS AND METHODS

Research Design:

A qualitative study design using interviews was utilized to explore the challenges and difficulties faced family of children with special needs at Taif city, Kingdom of Saudi Arabia. The interview were considered a suitable way for data collection as it allows interactions between participants and equip the possibility of acquisition multiple opinions and let the participant speak completely freely.

Setting:

Study was conducted at Taif club for people with special needs under the General Presidency of Youth Welfare which has licensed by the Ministry of Human Resources and Social Development that is keen to provide care, rehabilitation, diagnostic services, multiple therapeutic sessions including, communication, behaviour modification, skills development, physical therapy and awareness programs, and social and psychological counselling for people with disabilities and their families.

Study Population:

The population of this study includes all families registered at Taif club for people with special needs in Taif city.

The Sample:

All families registered at Taif club for people with special needs in Taif city were invited. A sample of 12 families caring for a child with different special needs were interviewed from March 2022 to April 2022.

Procedure of Data Collection:

The interviews were conducted according to the place and time which suited each family. The interviews were on average 40 minutes long and were audio recorded with permission from the participants, the audio-recordings were translated verbally into English by the translator after the interview and simultaneously transcribed by the first authors into written English transcripts. The written translations were verified against the audio-recordings for accuracy by the local supervisor. No significant incongruences or mismatches were found. Open-ended questions were used, such as "What does your son suffer from?", "Was the son able to deal with his health condition?", "In your opinion, what are the difficulties and challenges you have faced?" and "What are the needs of the family that has special needs?"

Ethical Consideration:

The researchers ensured to explain the research aim, objectives and all data collection processes to the families who were registered at Taif club for people with special needs. The information sheet and the consent form were delivered to the club. The families were informed that when they wish to participate, they must sign consent form and submit it to the club management. The form including all information about the study, the participants rights such as withdraw at any time, there identities remained confidential, and the data will be kept safely with the researchers. The researchers asked the participants before participating in the study if they had any questions and whether they had read the information form, and it was emphasized that participation in this study was purely voluntary.

RESULTS

The purpose of this study was explore the challenges and difficulties facing families with special needs, in which a number of (12) families of children with special needs participated. All participants were the biological mothers of their children and lived in one home with their family including fathers. 10 of them were Saudi nationality, 1 participant was Yemeni and 1 participant was Sudanese. In total, 12 participated children, among them 8 boys and 4 girls as in Table 1.

Most of the children participating in this study have special needs since birth. There are three of the participants whose children were disabled as a result of accidents such as a car accident or injury. Some of mothers were working to support their child and the rest of them were house wives; some of the children attended school, and others attended a day-care center. Others staying at home. The results of this study indicated two main themes: Challenges faced by children with special needs from the point of view of their families and the challenges faced by the families of children.

Table 1: Participants' characteristics

Participants	Age	Nationality
1	Male	Saudi
2	Male	Saudi
3	Male	Saudi
4	Male	Saudi
5	Male	Saudi
6	Male	Saudi
7	Male	Saudi
8	Male	Sudanese
9	Female	Saudi
10	Female	Saudi
11	Female	Saudi
12	Female	Yemeni

Theme 1: Challenges faced by children

Although the participants stated that the community understood the condition of their children, as seven of the participated parents answered that the community knew and understood the condition of the disabled, but some of the participants' families had their children exposed to bullying and they look to them with pity. These affected them greatly, and the community was unaware of the condition of the disability children, as stated below:

"As you know that we live in a society that has multiple cultures and different traditions, some of them are educated and some are not. Therefore, we as parents of children with special needs suffer. Because our children feel a lot of bullying by society and peers. But the beautiful thing is that we are as relatives of children with special needs, we understand that and we try to solve this issues immediately" (Participant 1)

"Children with special needs in society are exposed to a lot of ridicule and bullying specially from children, and this is clear to everyone" (participant 10)

"There are people in the community who are not aware enough of the situation of children with special needs and therefore it is easy for them to criticize and comment on the children and thus children feel disappointed in the society's consideration of their health conditions" (Participant 12)

The families of the participants indicated that there are many needs, such as the basic needs for their children, including psychological and material support, spreading awareness in the community and medical care, as they need to provide them with appropriate job opportunities as stated below:

"Praise be to God. In recent years, there has been interest in meeting the needs of those who suffer from health difficulties. However, there is still a need to find paths for wheelchairs in the city so that a person can move freely around the city without obstacles or

restrictions." (Participant 7)

"People with special needs have multiple health problems and may reach complications, and therefore they always need rapid, safe and continuous medical care." (participant 10)

"Despite the support spent on such a category from the government, it is not enough. Why? Because they simply need more health care and the provision of devices that maintain their health and facilitate their movement from one place to another. It is important to increase financial support, especially in the circumstances of the high cost of living these days" (participant 12)

Most of the families in this study mentioned that the children were able to adapt to society, but some of them faced some difficulties, such as the lack of community awareness of the child's health condition, as stated below:

"There are many people with special needs who are trying to adapt to society, but unfortunately the child is sometimes faced with the negative behavior from society in which they limit their capabilities and their work without full understand the child health conditions" (Participant 2)

"People with special needs always face daily problems with their community, but they continue to solve them and be able to overcome them. Sometimes they solve their issues on their own, and sometimes with the help of a family member. Therefore, its important to increase the community awareness about how to deal with children with health conditions" (Participant 9)

Theme 2: Challenges facing families of children

Most of the participants stated that they were deeply saddened and shocked by what happened to their children. Nevertheless, some of the participants stated that they received the news with complete satisfaction, as indicated below:

"We noticed on my son that he is different from the rest of his brothers and sisters. So, we as a family diagnosed him before the doctor because his behavior was not like his brothers. So, it was not difficult for us to hear the news. And we, as believers in God and destiny, we received this news with certainty that this is from God, and praise to God" (Participant 1)

"We as a family love each other. On the final diagnosis of my son's condition, I was shocked because it took so long to find out about his condition. This delay had a negative impact on him and on us" (Participant 2)

Participants also indicated that the absence of health rehabilitation centres, no health education for them, and the absence of medical supplies in the same city exhausts them psychologically and physically in order to provide that for children, as stated below:

"We are keen that our child receives adequate physical therapy so that his health does not relapse. Therefore, the large number of special needs with the

lack of health rehabilitation centers and specialists causes us anxiety, in addition, sometimes its difficulty of providing medical supplies in the same city" (Participant 2)

"There are many places where people with special needs need certain services, such as their need for someone who understand the sign language to meet their needs." (Participant 6)

DISCUSSION

The aim of this study is to explore the challenges and difficulties facing families of children with disabilities at Taif, Saudi Arabia. For this purpose, it is evident that parents of children with disabilities often experience rough paths when caring for their children. The participants have expressed their uneasiness when their child experience bullying and ridiculing from society. According to the study of AbdelHaleem (2020) society does not believe in the capabilities of children with disabilities. They are mostly underestimated and are viewed as abnormal and ought to be marginalize. Hence, the lower peer acceptance in public settings such as schools. This obstacle place the children with disabilities at higher chances of experiencing bullying (Berchiatti et al. (2022). Moreover, studies have stated that suffering from bullying develops chronic victimisation, which could progress a maladaptive behaviour resulting in family abuse, exclusion, and chronic social anxiety (González-Contreras, and Ramos-Sánchez, 2022). This is a serious long-term challenge for parents of children with disabilities, and interventions is highly needed. A study conducted in Finland indicated that good parental communication and teacher support at schools reduces risks of bullying and enhances the experience for children with disabilities (Bjereld et al. 2023). This also could majorly reduce the challenges especially for the parents.

On the other hand, this study found a raising community understanding and awareness towards the condition of their children with disabilities. This is a positive indication to an engorging awareness for individuals with disabilities and their families. The is due to the developing policies and procedures in Saudi Arabia for 2030 vision and increasing quality life for all people including children with disabilities and their families (Vision 2030 Gov, 2024). Though Saudi Arabia is moving towards a promising future for all people including parents and their children, it is no doubt that the perception of the society is still a challenge. For example, participants have shared their concerns at the alarming ignorance of society towards the rights of the children with disabilities. This is mostly because of the child's vulnerability, dependence, incapacity of judgement and lack of acceptance in society (Bergenmar, 2020). Furthermore, studies have found that non-disabled mainstream are often sustaining social distance, and regularly treating individuals with disability

as outsiders. Hence, triggering high social ignorance towards disabilities (Bohara, 2022). According to Farrell & Gloria (2015) these social distances should be reduced and solutions that can make society more aware such as, including disability in the curricula in schools and universities. Consequently, this could educate individuals in general on how to behave with people with disabilities.

Moreover, this study has observed that the participants financial struggles. This is because of the costs to maintain the needs of the disabled children. Similarly, Pasc (2017) study has mentioned that many families with disabled children suffer from difficult financial circumstances. In addition,

DiGiacomo et al. (2017) mentioned that among the expenses that these families may face include obtaining services, health supplies and transportation costs. It is also stated that access to specialized health service providers requires large financial expenses considering other family expenses. Consequently, individuals with disabilities become majorly affected by the limited aids they receive, which could worsen their condition. It was also found that the participants were searching for suitable job opportunities for people with disabilities to reduce the economic burden on their families. Correspondingly, the study of Owusu (2018) describes that parents of people with disabilities sould support their children's economical independency. However, this is difficult since they fear that jobs could not be suitable for their children's circumstance. Hence, the 2030 vision in Saudi Arabia had represented laws and legislations regarding the Disability Care Act, where the Employer Legal Requirement and Accessibility Requirement were established. This is to guarantee the rights of the populations with disabilities and their families to achieve appropriate employment opportunities and education (Vision 2030 GOV, 2022).

Rendering to the results of this study, it was indicted individuals who require the use of wheelchair suffer from the lack of accessibility to public faculties. This was a general problem faced by most people with disabilities because most countries do not have basic infrastructure that meets the needs of people with disabilities Noel, (2018). A study conducted in Riyadh had shown that the population who use wheelchair is significantly lower in comparison to the high population in the city. Therefore, the use of wheelchair issues is easily be disregarded. The study further explained that parking lots were overly crowded and not industrialised to accommodate wheelchair users. Therefore, often people needed assistance from a caregiver to drive them to the front of public places, leave the care, and place them in a wheelchair to enter the place (Gansham et al. 2018).

This study also indicated that some children with disabilities have difficulty communicating with others. DiGiacomo et al. (2017) explained this is because the disabled child has aggressive behaviour which makes it

difficult to communicate with society and also disrupts family harmony. This has great physical and psychosocial pressure for the parents. Therefore, providing the parents with counselling to introduce alternative ways of communicating with their children with disabilities to develop a better understand and containment towards the aggressive behaviour.

CONCLUSIONS

This study aimed at exploring the challenges of parents of children with disabilities. The study concluded many challenges and obstacles parents of children with disabilities face. For example, the bullying the exclusion children with disabilities face in schools and in society in general. Research have found the bullying the exclusion from the society could create long-term negative impact on the individuals and their parents. This study also found that parents experience the lack of social awareness regarding their children with disabilities. Hence the importance of promoting social awareness, and the implementation of policies and procedures regarding children with disabilities and their parents.

Supplementary materials

The supplementary material / supporting for this article can be found online and downloaded at: <https://www.isisn.org/article/>

Author contributions

Conceptualization, R.A., A.K., and A.M.; methodology, A.K., R.R., H.A. and S.A.; validation, A.A. and A.M.; formal analysis, R.R., H.A, and A.M.; data curation, R.R, H.A, S.A, A.A.; writing-original draft preparation, R.A.; writing-review and editing, A.M. and R.R.; supervision, A.k.; All authors have read and agreed to the published version of the manuscript.

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It is available on request from the authors.

Conflict of interest

The authors declare no conflict of interest.

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