

The Role of Information and Communication Technology in Autism Care

Case Study: Sudan

by

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ABSTRACT

This research aims to serve as a starting point to the exploration of the current status of autism in Sudan and how to best utilize available Information and Communication Technology (ICT) to educate and support parents and educators. Currently, there is no official published data on the prevalence of autism in Sudan or the related available services and facilities. To attempt to expand upon the limited existing knowledge, the researcher collected all available data and information through Sudanese Facebook groups and pages. The research was observational in nature. Findings indicated that raising a child with Autism Spectrum Disorder (ASD) in Sudan can be rather challenging, particularly for parents who do not have easy access to ASD treatment. In general, parents in this study expressed minimal satisfaction with the available treatments and services that their children were receiving. Parents repeatedly addressed problems regarding a lack of access, the overwhelming expense, and the need for more awareness and acceptance of autism within Sudanese society. In response to these issues, some of the parents formed small support groups and met regularly to share experiences and discuss solutions. Additionally, some parents are creating discrete Facebook pages to help normalize autism and combat misinformation.

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CHAPTER 1

INTRODUCTION

Autism Spectrum Disorders “ASD” is the current term used to categorize a set of complex, neurodevelopmental disorders that drastically impair a person’s behavior as well as their social, interpersonal, and communication skills. Autism profoundly impacts the affected individual, and beyond that affects the family and caregivers. In many cases, ASD also affects the communities in which people with ASD live, attend school, and engage in both socially and educationally.

The World Health Organization “WHO” has determined that approximately 1 in 160 children are diagnosed with ASD (WHO, 2017). While estimates of ASD prevalence are on the rise, the occurrence of ASD appears to be universal and the contexts in which it occurs are distinctive. Despite ASD being reported to occur in all racial, ethnic, and socioeconomic groups, little research has been conducted on ASD in developing countries, with little reliable information yet reported from developing countries. In fact, most of the current research into ASD has been conducted in affluent, English-speaking countries, which already have extensive professional support services.

The increased prevalence of ASD estimates world-wide draws attention to this issue and makes it pertinent to identify the needs of individuals diagnosed with autism, especially in developing countries. Furthermore, the concern over increased ASD prevalence, combined with growing public awareness, has highlighted the need for a better understanding of the ASD condition in general; ASD symptoms; and ASD appropriate treatment. According to the WHO, however, there is a lack of knowledge about the barriers in health systems that hinder the delivery of ASD interventions, and the strategies

required to overcome them. The WHO has determined that further basic research is needed to develop better interventions and achieve the millennium goal

of global health equality (WHO, 2017; Collins, Joestl, S., March, D., Insel, T. R., & Daar, A. S. 2011).

Health inequities are unjust and avoidable. Taking meaningful action towards achieving health equality is not only a moral imperative but is also undeniably beneficial to society. Working to resolve health inequities, enhances population health, improves economic and living conditions, and therefore advances social justice. Addressing this issue, a consortium of researchers, advocates, and clinicians has announced research priorities that call for urgent action and investment in improving the lives of people with mental illness around the world (Collins, P. Y., Patel, V., Joestl, S. S., March, D., Insel, T. R., & Daar, A. S. 2011). Specifically, the National Institute of Mental Health's (NIMH) initiative, Collaborative Hubs for International Research in Mental Health, has committed to support research on the use of non-specialist mental healthcare providers and research training in low- and middle-income countries. Although research in this field may seem to be incremental progress in addressing the grand challenges in global mental health, the information gathered could be the first step that leads to significant economic and quality-of-life benefits - including reductions in inappropriate use of healthcare and increased productivity for years to come- that would far outweigh investment costs (WHO, 2017).

The issue of healthcare inequity is especially apparent in the northeastern region of Africa. In Sudan, there is no epidemical study or official data available on the magnitude

of ASD (Babikir, 2014). This is because autism was not the subject of interest in the region until the late 1990s (Babikir, 2014). Lack of cultural awareness of ASD and interest as well as a lack of medical resources are some of the largest driving forces behind the unmet needs of individuals diagnosed with autism in the country. In order to appease this issue and better support the population of individuals diagnosed with ASD in Sudan, more research is essential. Research is crucial; specifically, it aids in better identifying the burden and risk factors of autism in Sudan. Knowing the burden and extent of disease, would also be integral in the design of screening tools that are applicable, culturally acceptable, and cost-effective. These tools would be of potentially high impact as they would allow those administering the screening to identify the individuals who are able to benefit the most from early diagnosis and intervention. Furthermore, as ASD is a lifelong disorder, raising ASD awareness among parents, pre-school/elementary school teachers are invaluable in reaching and helping autistic children cope with different challenges at a critical young age.

Information and communication technology “ICT” may play a big role in closing the knowledge gap on global health inequality that stems from some form of discrimination or lack of access to certain resources. Often, inequitable health outcomes are systematically experienced by population subgroups that are disadvantaged due to factors such as economic status, education level, gender, place of residence, race, ethnicity, age, or disability status.

WHO recommends the use of ICT to support developing countries in the diagnosis and early treatment of autism spectrum disorders and other developmental disorders? ICT has already been established as a particularly cost-effective means of assisting families when

professional resources are scarce as is the case in many low-income countries (WHO, 2014). As ICT has already been proven effective, this research will explore the possibility of using ICT to examine the potential of providing education and training to groups of parents, teachers and health care workers as a means of promoting the children's development and in meeting parent's needs.

This research advocates health equity and strives to improve the situation of ASD services in Sudan by both ensuring that Sudanese parents have access to necessary health interventions and addressing the underlying causes of discrimination and disadvantage. Hence, this research is being developed foremost in response to the ongoing community concerns on the rising prevalence of ASD in Sudan and aims to explore, evaluate, and establish the prevalence and magnitude and trends of ASD in Sudan and to quantify available help resources and the availability of equipped schools and Autism treatment centers.

CHAPTER 2

LITERATURE REVIEW

There is an absence of cures and a dearth of preventive interventions for Mental, Neurological, and Substance use disorders (MNS). This is because there is currently a rather limited understanding of the brain and its molecular and cellular mechanisms in regard to MNS disorders. Even where there are effective treatments, they are frequently not available to those in greatest need. Unequal distribution of human resources - between and within countries - further weakens access to health services. One such example can be seen in the field of psychiatry. In fact, the European region has 200 times as many psychiatrists as in Africa (Hosseinpoor, Bergen, Schlottheuber 2015). Across all countries, investment in fundamental research into preventing and treating MNS disorders is disproportionately low relative to the disease burden.

Treatment may differ as Autism Spectrum Disorder (ASD) refers to a group of complex neurodevelopmental disorders characterized by repetitive and characteristic patterns of behavior and difficulties with social communication and interaction (NIH, 2018). More specifically, ASD includes several conditions that used to be diagnosed separately: Autistic Disorder, Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS), and Asperger Syndrome (NHI,2018).

These conditions share several similar, defining characteristics which are present in the form of abnormal functioning in three primary areas: social interaction, communication, and restricted, repetitive behavior. These ASD symptoms are present from early childhood and affect daily functioning. Some children and adults with ASD are fully able to perform all activities of daily living while others require substantial support to perform

basic activities. However, across the board, on the outside, there is often nothing about how those with ASD appear physically that sets them apart from their unaffected counterparts. Differences become apparent in their mannerisms as individuals with autism may communicate, interact, behave, and learn in ways that are quite different from most other people and may be anything from severely challenged to extremely gifted intellectually (NIH, 2018).

It is important to note that ASD occurs in every racial and ethnic group, and across all socioeconomic levels. However, there are certain groups in which autism is more prevalent. In regard to gender, boys are four times more likely to develop ASD than girls (National Autism,2017). Additionally, the numbers of children diagnosed with ASD throughout the world has been expected to rise in the upcoming years. However, as of now, most families, and especially the general public, remain rather ignorant about the implications of ASD and the likely impact it will have on the child's development and on family life.

There is a big gap in epidemiologic data and management of ASD between developed and developing nations and Sudan is no exception. Therefore, there is a great need for international bodies to increasingly drive the global advocacy action for individuals with ASD. An initial, superficial search on the internet shows that there are many international websites that offer a resource guide in which families of individuals with autism can find support including adult programs, financial resources, community- support organizations, health services, and interventions for toddlers, children, and adults. Increasing public awareness of autism in the developing countries must be prioritized. Unfortunately, autism awareness is low, especially in Sudan.

Obtaining reliable data about autism from developing countries is challenging as autism awareness differs from country to country; available services for individuals with autism and their families also differ. Although it may be potentially difficult, obtaining information on the identification of children with ASD in different countries and cultures can serve a number of uses. Parents in developing countries have little opportunity to obtain information about ASD through any of the conventional means that are accessible to those parents in western countries. In these cases, ASD knowledge programs would be an effective, alternative method of support for parents as it would help parents to be able to develop pertinent skills and gain the necessary information to both increase their children's communication skills and to decrease their kids challenging behaviors.

Moreover, having a support system consisting of group discussions and activities provide parents with an opportunity to share their stories, knowledge, and experience of ASD for both symptoms and treatment.

As research for ASD has increased in the US, there is growing concern regarding whether it should be used to further basic research, which is generally considered to answer more long-term questions, or whether it should focus on remediation research, which is more short-term oriented (Cho 2011). This question of which type of research to support is even more pertinent in Low- and Middle-Income Countries (LMICs), where the funding and research is more limited. More specifically, there is question of whether research should focus on prevalence, risk factors, genetic associations, or intervention practices.

While there is no longer a need to continue to justify the potential impact of ASD studies (e.g., Bernier et al. 2010; Grinker et al. 2011), more funding mechanisms are now in

place to facilitate research that is expanding knowledge of ASD and acts as a source for additional learning (Daley, T.C., Singhal, N. & Krishnamurthy 2013).

In order to allow for the growth of ASD research globally, some suggest research should emphasize the needs of families, children, and adults affected with autism while also addressing broader issues, as there are economic and political constraints in LMICs (Daley, T.C., Singhal, N. & Krishnamurthy 2013).

Background on Autism in Sudan:

Sudan is located in the northeastern region of Africa with a total area of 1,882,000sq. km. Sudan has international borders with seven countries: Egypt, Eritrea, Ethiopia, South Sudan, Central African Republic, Chad and Libya. Sudan is located in the Sahara Desert and is situated near the Middle East. Sudan is one of the poorest nations in the world with a weak economy and infrastructure. Sudan is currently experiencing big changes as the longtime dictator Omar al-Bashir was officially removed from office April 11, 2019 in the face of massive demonstrations. Social media has been the driving force in Sudan's revolution, providing people with an opportunity and avenue to organize and mobilize against the former regime as well as alert others to these dynamic events. The Sudan revolution was another proof on the important and effective role ICT can play on spreading information fast and in a cost-effective manner.

Autism is a growing problem worldwide and possesses a great healthcare and economic burden upon the families and the governments in which the affected populations reside, especially in developing nations such as Sudan. Prevalence of ASD has increased in Sudan over recent years, but despite this, there is no official data on the magnitude of it.

In fact, rather little is known about the identification and management of ASD in Sudan. The majority of research in the field of autism has been conducted in Western countries. In the developing countries and specifically in Sudan, autism has not been a subject of public or governmental interest. As the prevalence is on the rise, it is especially crucial that more research is conducted in order to meet the rising need of those with autism in Sudan. As currently there is little known about the disorder, this will be a rather large undertaking.

Sudan's Healthcare System:

Sudan has a well-established healthcare system with many drawbacks mainly due to economic and managerial reasons followed by prolonged political instability and sanctions (Ebrahim, Ghebrehiwot, Abdalghar, and Juni, 2017). There are scarcities in mental health services at all levels in terms of availability, accessibility, and affordability (Ebrahim, Ghebrehiwot, Abdalghar, and Juni, 2017). There is also shortage of human resources and trained mental health professionals especially in rural areas (Ebrahim, Ghebrehiwot, Abdalghar, and Juni, 2017). According to Suleiman 1985, one of the biggest challenges Sudan faces is the strong social stigma against people with mental disorders especially in rural areas. In rural areas, help for a person with a mental disorder is first sought secretly from an indigenous practitioner who is usually a faith or a religious healer, or a "Zar" spirit exorcist or "Kujur" therapist (Suleiman, 1985). Hence, families in Sudan carry almost all the burden of care for individuals with ASD within the cultural settings of their societies. All this depending on the ethnocultural

background of the patient. Therefore, changing these concepts will be instrumental in implementing treatment. The issue of stigmatization should also be addressed so as to improve case detection. Better still, support from friends, families, and professionals is critical to enhance the psychological well-being of caregivers experiencing stigmatization.

In Sudan, educational and behavioral interventions for childhood autism are largely unavailable and the lack of mental healthcare facilities and adequately trained personnel falls short when it comes to the estimated number of autism cases. In primary surveillance survey with parents, autism centers, and teachers, researcher observed that health care workers and teachers were to have low to average knowledge and awareness of ASD. Two treatment centers were contacted, 32 parents were interviewed, 10 educators were interviewed, and all confirmed their dissatisfaction with the quality of service and the knowledge of workers. None of the teachers in those centers is a board-certified behavioral analyst or works with one. The role of the Board-Certified Behavior Analyst (BCBA) is critical in the treatment or management of behavioral, emotional, and developmental disorders. In more developed countries, ASD interventions are administered by psychologists, as well as by educators and board-certified behavior analysts.

Training on ASD interventions is especially important for parents. Parents spend more time with their child throughout the day, evenings, and weekends than any service provider, they are able to provide “around the clock” intervention for their child.

Additionally, parent education can address the issue of generalization, given that service providers often only see children in a restricted number of settings, such as a clinic room

or a classroom. Research has documented that parents have been able to learn strategies to effectively teach their children with autism across a variety of areas, including reducing problem behaviors, decreasing restricted and repetitive behaviors, improving communication, improving social skills, and improving self-help skills such as toilet training (Schultz, T. R., Schmidt, C. T., & Stichter, J. P. 2011).

The increasing frequency with which children are diagnosed with ASD and other neurodevelopmental disabilities highlights a significant need for ongoing developmental screening, early diagnosis, and timely early intervention services and supports in culturally and linguistically diverse communities. Each community is unique in culture, values, and perceptions of disabilities such as ASD and the practices of a community must be taken into account when considering implementing possible interventions (Taha, Hussein H. 2014).

Early screening of ASD and Diagnosis:

Research shows children who receive autism-appropriate education and support at key developmental stages are more likely to gain essential social skills and react better in society (CDC, 2018). The diagnosis of ASD is found to be much delayed in developing countries compared to developed countries, this being a result of the lack of awareness, necessary skilled professionals, and facilities (Ahmed, N., Raheem, E., Rahman, N., Khan, M. Z. R., Mosabbir, A. A., & Hossain, M. S., 2018). Parents, family members or other caregivers of children with ASD have proven to be viable early screeners in developing countries as they are often the first to notice delays in the usual childhood

developmental milestones such as speech, eye contact, play with other children or social interactions (CDC, 2018).

According to the National Institute of Health “NIH”, the severity of ASD on children can vary greatly from one child to another (NIH, 2019). Children with ASD are usually overly focused on certain objects, rarely make eye contact, and indifferent to social interaction. (National Institute of Neurological Disorders and Stroke, 2018).

Autism Treatment:

There is no cure currently for ASD (NIH, 2018- CDC, 2018). The most effective treatments available today are Educational/ Behavioral interventions, Occupational therapy, Speech therapy, Physical therapy, and Pharmacological therapy (American Psychiatric Association, 2013).

Educational/behavioral interventions:

Early behavioral/educational interventions have been very successful in many children with ASD (American Psychiatric Association, 2013). According to Welsh, ABA has proven effective for a number of reasons: ABA is individually customized, ABA can be implemented in a variety of settings, ABA can help those with autism to develop better social skills, memory, and attention, and it can help to reduce negative behaviors (Walsh, 2011). Recent data shows that there are only 29104 ABA experts, called Board Certified Behavioral Analysts (BCBAs), worldwide (BACB certification data, 2018). ABA therapy is only accessible in about 20 countries (BACB certification data, 2018). As autism is present worldwide, the availability of ABA therapy and therapists must also be worldwide.

Occupational Therapy: The three common areas OT can help with are emotion regulation skills, social skills and peer interactions, and sensory processing as it is estimated that between 50 and 70% of children with autism have difficulty with sensory processing (Case-Smith, Arbesman, 2008).

Speech Therapy: Speech therapy may help in improving spoken language, learning nonverbal skills such as signs or gestures, or learning to communicate using an alternative method (such as pictures or technology) (Autismspeaks.org, 2019).

Physical Therapy: Recent research findings suggest that many children with ASD demonstrate delayed and atypical motor achievements. It is crucial to ensure that this group of clients has access to early physical therapy (PT) interventions (Daley, T.C., Singhal, N. & Krishnamurthy, V. J, 2013). Physical therapists work with parents to monitor how child progresses and collects data to make sure that the treatment plan is leading to positive outcomes for the child (APTA, 2019).

Diet for Autism: Because children with ASD often have restricted diets as well as difficulty sitting through mealtimes, they may not be getting all the nutrients they need, particularly calcium and protein (Kałuzna-Czapłinska, Jozwik-Pruska, 2016). According to Cermak, Curtin, & Bandini 2010, some common food challenges parents reported for children with ASD include sensitivity to the taste, smell, color and texture of foods, difficulty focusing on a meal, constipation, and decreased appetite due to medication interaction. Special ‘exclusion’ diets used to help people on the autism spectrum include the Gluten-free Casein-free diet GFCF and the Feingold diet (Legge, 2002).

Information and Communication Technology:

Over the recent years, there have been increasing opportunities for inhabitants of developing countries to use Information and Communication Technologies (ICT) (Crespo, Martin 2018). Even in light of this expansion in technology adoption rates, penetration rates differ markedly between developed and developing countries and across developing countries.

Information Communication Technology (ICT) refers to the collection of devices and resources that allow for the secure storage, retrieval, manipulation, and communication of electronic information. ICT has been implemented in a variety of fields to increase productivity, improve functionality, allow for easier accessibility to information, and help to lessen resource disparities. ICT has the potential to tackle a wide range of health, social and economic problems (Crespo, Martin 2018). By improving access to information and enabling communication, ICT can play a role in fighting poverty, combating diseases and other health problems, and accomplishing better educational outcomes (Crespo, Martin 2018).

Social networking through social media platforms employs the Internet in acting as an ICT. Social media enables individuals to form and maintain connections as well as share information and content. Interactions between individuals on social media are generally facilitated through friendship, common interests, work, knowledge, prestige, which are sometimes referred to as the “nodes” of the network (Valdez, Guterbock, Fitzgibbon, Williams, Wellbeloved-Stone, Bears, Menefee, 2017). Varying by field and expertise, social networks can generally be classified into one of the following groups: a) social networks with personal physical connectivity, b) global social internet networks, c) specific health internet social networks, d) the health community internet networks of

non-professionals, e) scientific social internet networks, f) social internet networks with supported professionals, g) scientific medical internet network databases in the system of scientific and technical information (Valdez, Guterbock, Fitzgibbon, Williams, Wellbeloved-Stone, Bears, Menefee, 2017).

Networking using social media, as well as direct interactions among parents of autistic children appears to be an effective means of sharing and providing updated information on ASD care to the concerned parents (Ahmed, N., Raheem, E., Rahman, N., Khan, M. Z. R., Mosabbir, A. A., & Hossain, M. S., 2018).

The role of ICT in illness management and information acquirement regarding an illness or disorder has been previously researched through social media platforms such as Facebook. One study exploring health information communication patterns on and off Facebook involved analyzing and profiling the practices of 700 participants diagnosed with Type 2 Diabetes. Through detailed surveys, researchers were able to typify the behavior of the participants through 7 distinct profiles that examine health information communication through the lens of 6 key categories: altruism, instrumental support, privacy and stigma, social support, convenience, and Facebook knowledge (Nadine, 2017). Findings indicated that despite the means through which participants communicated health information to be quite diverse, Facebook was a widely utilized resource.

Another study specifically examines how status updates on Facebook regarding mental health offer the opportunity for intervention and potential treatment and prevention of mental illness. In one study, focus groups comprised of college students were organized to gauge user impressions of mental health references in the posts of their peers. The

findings were quite diverse, ranging from viewing references to be serious to assuming references were jokes. The views were linked with the person's relationship as the findings demonstrated that if the student had a closer relationship with an individual, they were more likely to view posts with references to mental illness as serious and more likely to personally reach out. Additionally, such posts on Facebook allow for the identification of those who may be at risk for mental illness through the recognition of possible symptoms and presents the opportunity to "provide them with confidential, online resources or information about offline access to care" (Nadine, 2017). While Facebook can foster the creation of support networks, there are concerns of privacy. However, in order to appease concerns, Facebook has allowed group settings that allow users to adjust to their preferred level of privacy. Groups set to secret are private and hidden in search, groups set to closed are private and visible in search, those set to public are public and visible in search (Facebook, 2019).

Beyond Facebook, when used correctly, ICT can additionally support learning and education for children with ASD and improve their vocabulary and communication skills. Researchers additionally recommend incorporating primary ASD screening into the existing vaccination platform, educating and training parents of autistic children, and adapting ICT-based solutions In order to maximize resource usage while minimizing costs and to create opportunities for policy makers to evaluate the existing system, (Ahmed, N., Raheem, E., Rahman, N., Khan, M. Z. R., Mosabbir, A. A., & Hossain, M. S., 2018).

Although there is little existing data on technology usage in Sudan, the large role social media and technology played in the April 2019 successful change of government in

Sudan suggests that there may be an opportunity to develop and implement ICT-based intervention tools. In a LMIC such as Sudan in which the culture varies vastly from Western culture, such tools must be culturally adapted to meet the needs of caregivers and children while maintaining accessibility. Such tools could increase awareness and connect communities.

Developments of Sudan's telecom sector began incrementally in 1993 and were greater after the discovery of oil in 1997, which helped to increase foreign exchange.

Telecommunication density a Compound Annual Growth Rate (CAGR) of 40%, Sudan's fixed telephone market is not only the fastest in Africa but worldwide.

Telecommunications investment has skyrocketed from only US \$500,000 in 1994 to over US \$100 million per year. There is still great potential for continuing growth as the country's telecommunication density remains one of the lowest in the world at 3%. While internet penetration is still rather low at 29.6%, mobile penetration is much higher at 71%, according to the latest available data from the International Telecommunications Union (ITU). A majority of internet access is actually done through mobile devices, although only 22% of Khartoum residents have smartphones, compared to 9% of the total population. (Lancaster, 2019). This reinforces that there is an opportunity for the implementation of ICT tools.

Within the various methods and tools of early intervention in people with ASD, ICT has proven to be beneficial, and there have been great advances in research on ICT for education of people with special needs (Konstantinidis et al. 2009; Crespo, Martin 2018). Education in the early stages of ASD has proven useful in coping with difficulties in understanding what other people communicate (Howlin and Asgardian 1999; Crespo,

Martin 2018). Thus, there have been innovations in approaches and methods based on ICT for therapies and education of children with ASD, which has recently been included as a focus in ICT focused on social signal processing, whose objective is to provide computers with the ability to detect and understand social signals and communication (Crespo, Martin 2018). It has also been included in ICT focused on affective communication, which seeks to model, recognize, process and simulate human affections (Crespo, Martin 2018).

In general, ICT are adequate for the visual thinking of people with ASD; can help those who are not verbal; they constitute a convenient auditory material, provide multiple inputs of data suitable for different types of skills; they are adaptable to sensitivity (auditory, tactile, visual) and offer various communication channels (Crespo, Martin 2018).

Within the ICT, given the accelerated growth, accessibility and commercialization of personal mobile devices (smartphones, tablets, Ultrabook), the applications for these devices focused on supporting people with ASD proliferate, mainly in terms of the early development of imitation and joint attention (Crespo, Martin 2018) with diverse treatment objectives, highlighting: interactive environments, virtual environments, avatars, serious games and tele-rehabilitation (Crespo, Martin 2018). Crespo and Martin classify applications for ASD treatment according to their main objective:

- (1) Support technologies that counteract the impact of sensory and cognitive alterations of life related to autism;
- (2) Cognitive rehabilitation / remediation seeking to modify and improve the basic deficit in social cognition;

(3) Special education programs to counteract the difficulties of children with ASD in the acquisition of social and academic skills;

(4) Support tools and processes for parents, guardians, caregivers and / or professionals.

ICT has created new ways to help people with ASD. The provision of accurate ICT through accessible media and local languages is essential to combatting this issue. ICT creates otherwise unavailable opportunities for families to receive the most up-to-date treatment and methods as well as ongoing emotional support.

CHAPTER 3

METHODOLOGY

The study's methodology was primarily qualitative and, as such, more exploratory than hypothesis driven. After initially speaking to Sudanese parents and educators, it was determined by the researcher that Facebook pages would serve as the most appropriate to collect data. Specific aims of the study included gaining a better understanding of: (a) Current knowledge and training regarding the characteristics kids with ASDs (b) Available treatment procedures for parents and parents expectations from these treatments for their child's future, (c) What role ICT (specifically Facebook- a social media platform enabled by ICT) could play on meeting parents with ASD children needs, (d) familiarity with and use of the available evidence-based interventions for students with ASDs, and (f) awareness, views, and opinions on parents.

The perspective of both ASD parents and professionals was gathered through the collection of relevant data. Given the continual increase in prevalence rates of children with ASDs, it was assumed that at least one teacher in autism treatment centers, if not more, would have had at least some prior knowledge and/or experience on APA intervention techniques.

The trail search was conducted by using the following search string in Facebook using Arabic and English language:

1. "Autism in Sudan" or "التوحد في السودان"
2. "Autism Spectrum Disorder Sudan" or "اضطراب طيف التوحد السودان"
3. "Children with autism Sudan" or "الأطفال المصابين بالتوحد السودان"
4. "Asperger Sudan" or "اسبرجر السودان"

5. “Behavioral Disorder Sudan” or “الاضطرابات السلوكية السودان”

6. “Neurobehavioral disorder Sudan” or “اضطراب السلوك العصبي السودان”

7. “Developmental disability Sudan” or “السودان ذوي الاحتياجات الخاصة”

Moreover, the researcher visited all Facebook pages mentioned by Sudanese parents in Facebook and all relevant posts. Throughout the study, the confidentiality of the identified subjects was carefully protected, and no names were used unless a person had made a public post.

Research Questions:

- What role does Facebook have, if any, in Autism Spectrum Disorder in Sudan?
- Once a diagnosis has been received, what services and treatments are available in Sudan?

CHAPTER 4

DATA AND FINDINGS

Facebook posts included discussions initiated by parents, teachers and doctors. Those posts revealed that the beliefs about the causes of autism in Sudan greatly varied. The overall posts reflected that most parents did not know or were unsure about what caused autism. There was no single explanation about the specific causes of the disorder that appeared to be the dominant view amongst the posts. The explanations offered by parents, teachers, and doctors for what might cause ASD included genetics, environmental pollutants, religious and spiritual reasons etc. Some of the parent's beliefs on the causes were scientific- including genetics, issues related to pregnancy, and environmental factors. Comparatively, only a few parents, less than 20%, believed that autism is caused by the evil eye or "Al-ain". The term "Al-ain" usually refers to a cultural superstition that suggests that harm is brought upon a person because of someone else's jealousy or envy towards them. Only two parents mentioned vaccine and specific environmental toxins as potential causes for autism. In general, most parents in this research expressed confusion and a lack of knowledge about what caused their child's disability. Many parents shared their impressions of how severe or mild their child's autism seemed to be, despite that being something that is only measurable by a professional. All parents agreed sought schooling and treatment for their children with autism.

All parents and professionals acknowledged that awareness and understanding of autism spectrum disorders in Sudan was growing every day. In general, parents in this study showed minimal satisfaction with regards to treatments and services that their child was

receiving. While on the one hand parents acknowledged increasing awareness and acceptance as well as the increased availability in resources, on the other hand, parents consistently addressed problems with access and expense and the need for more awareness and acceptance in the society. Parents emphasized the need for greater knowledge regarding the disorder in the general population as well as a more urgent need for more familiarity with the disorder amongst school personnel and those working in education. Parents expressed feelings that autism is a stigmatized topic in Sudanese society and that there is a general expectation to not explicitly discuss the disorder. Parents felt this to be a large contributor to the misinformation regarding autism and a majority shared that autism being deemed a taboo subject was an everyday hindrance in their lives.

Additionally, parents and professionals almost uniformly addressed a myriad of difficulties that significantly impacted their everyday lives and outcomes for children on the autism spectrum. Many parents expressed concern about the lack of available resources available to them such as specialized therapists and educators. Due to the lack of resources, the few available are rather costly and many parents expressed dissatisfaction at this situation. Resources are additionally not well-advertised which caused many parents to have issues with accessibility. Parents who shared these grievances voiced a need for more services for children with ASD for this reason. Due to the lack of early screening tools available, many parents shared they were unable to receive diagnoses for their children until a later age. Due to this, many parents and professionals expressed worry that autism intervention in Sudan currently targeted only the younger children, and that there were very limited options for what services may be

available to their children when they become adults. One post of a Sudanese family relocation back to Sudan was asking about a center for an adult who is 20 years old. Professionals expressed a need for more training in the field and access to higher quality of resources, while parents wished that the government did more to help their families. The researcher was able to speak with families whose children were already identified with an ASD and were receiving services. However, we can only assume that there are many more children who are underdiagnosed, misdiagnosed, or simply missed in the bigger picture. Given the vast diversity in culture and economic standing of families, geographical spread of towns, villages, and cities in each state, and the rapidly increasing population, the task of providing diagnostic and intervention services for all children who have an autism spectrum disorder in Sudan is an almost impossible task at the current time. However, Facebook posts provided the researcher with valuable information about where some of those gaps exist and how we can begin to think about addressing those gaps in incremental, systematic steps in the future.

One of the most watched live videos about autism that the researcher found on the Facebook search was by Tamador Elhassan. Tamador is a Sudanese psychiatrist who resides in the UK and posts about different topics. The most watched live video was the two hours and four minutes she posted on September 2018 about Autism. The number of views on the video was 44 thousand and the number of likes was 1.9 thousand. This video was shared 307 times. The video was in Arabic and five parents participated live in the video. The live video included information on detecting early signs of autism, explored the impact of autism on families, dismantled common misconceptions about autism, and discussed some intervention techniques. It broke the stereotyping and having

parents participate and share their experiences was great. One of the parents who participated in the video talked about autism affected his relationship with his wife and how he now has great appreciation for her. His part got a lot of attention and people were sending his family prayers and gratitude.

Most of the comments on the video was positive and parents showed great appreciation for the information. There was no follow up video on ASD after that.

The researcher is a member of a closed Sudanese group with 13,522 all female members. This is a private group and only those who have been invited to the group can see the content and information shared within it. The group has strict rules about privacy and to join you will go under verification and recommendation process. The group currently has a long wait list. This group will be referred in this research as Group A. Group A is very selective in choosing their members and it could take over a year before your request is processed. The group includes Sudanese women of all professions living all around the world. The researcher searched autism posts and found 45 posts about children with ASD. The average number of comments on these topics was 15, with the average number of likes being 70. Five moms created support groups where their children of ASD can meet and play. These moms meet at one of the mom's houses monthly to learn about ASD treatment options and to share experiences. Also, a group of moms created a WhatsApp group where women can share knowledge and find answers. Both served as support systems for the mothers.

There was a post in Group A that received 70 comments. The post was about the case of a 3 years old autistic girl named Ludan. Ludan was very active and nonverbal. Ludan's mom enrolled her in a neighborhood kindergarten thinking that if Ludan socialized with

the other kids, then Ludan would learn how to better socialize and pick up some vocabulary words. Ludan was very active and wouldn't sit in her chair. This was an ongoing issue with Ludan, so without having any knowledge on ASD intervention methods or a proper occupational therapist the teacher and the principal decided to tie Ludan to her chair. This practice was done daily until one day the mom noticed some marks on Ludan's legs. Ludan's mom went to the neighbor and asked Ludan's classmate and that is when she discovered what has happened. When the principal and the teacher was questioned, they said that they believed that they were actually doing Ludan good rather than harming her. The mom pulled Ludan out of kindergarten and again enrolled her in. The commenter's reactions differed. About 91% voted that Ludan's mom should take legal action. Almost 70% of the participants were blaming the government for not providing the necessary training for teachers. 33% blamed the mom for not seeking professional help and reenrolling her kid again in a school with no trained staff.

Another Sudanese mom created a page on November 10, 2015 called "This is me". The Facebook webpage link is: <https://www.facebook.com/This-is-me-496859393808463/>. This webpage contains a series of short diaries of a 4 years old autistic written by her mom. The mom kept her identity and her daughter identity's discrete. The page has 5,805 followers but the interaction on the page is fairly low. There are 211 posts with an average of 52 likes and 29 comments.

Recently, there has been a growing number of schools specialized in treating autism. According to posts, none of these schools has a certified APA professional. Many moms reported their continued dissatisfaction with the school. In the last year, three reported that they moved to the UK, UAE and Egypt to seek better treatment for their children. A

majority of parents also spoke about their desire for the child to be accepted in the society.

While there were many educational posts about ASD treatment centers, the researcher was not able to find any regarding occupational, speech or physical therapy. Many moms shared the similar thought that they felt like their children would learn best from being around other kids and having one on one attention from their teachers. At least 40% of the moms complained about the high cost of attending specialized ASD treatment centers.

Moreover, there was only one post in regard to pharmacological therapy. The post had no likes and only two moms openly expressed support of using medication to help control of ASD symptoms.

There were two posts about ASD treatment involving different nutrition discussing that included the Gluten-free Casein-free diet GCFC and the Ketogenic Diet KGD. Both received two likes but no comments. Some parents, however, shared how they have implemented special routines and diets with their children outside of the school setting. These included taking them to the beach for them to feel the sand on their feet or avoiding certain foods to control allergies or weight-related issues.

In general, parents, teachers, and doctors were influenced by the broader cultural context in terms of selecting what treatments to use with the children and saw value in using a multi-pronged and combined approach to treatments and interventions.

Doctors and professionals living in the United States noted in many posts the importance of developing programs for children with autism in Sudan and felt implementing Western-based treatments, in the areas of special education, speech and language therapy,

occupational therapy, with little to no guidance or training . would not prove successful. This is as Sudan lacks the infrastructure needed to implement such treatments effectively. These professionals stressed the need for developing more culturally appropriate and culturally effective treatment programs, programs that take into account the country's long and rich history and unique systems of healing and medicine.

Weaknesses and strengths of the Study:

There were a number of acknowledged weaknesses and strengths manifested in various aspects of this study. They are as follows:

Weaknesses:

- There is no other study available on this issue involving solely the Sudanese community. Therefore, there is no baseline data or other available information for reference and support for this research.
- Researcher had access only to the families who posted in Sudanese Facebook groups.
- Research excluded parents who don't have access to Facebook.
- Consequently, the study population offers an exploratory look at the problem, with issues of generalizability unaddressed.

Strengths:

- As the researcher herself is a Sudanese native, from the same cultural and social background as potential respondents, this provided easy access to Sudanese only Facebook groups.

- Facebook posts facilitated the gathering of information that is thought to be an authentic expression of the experience of participants while protecting confidentiality.

CHAPTER 5

CONCLUSIONS AND FUTURE DIRECTIONS

Our study provides new information about the use of Facebook, a social media platform enabled by ICT, in communicating information regarding autism. In the wake of Sudan's technological advancements, there is an increased capacity for parents and professionals to access the information that they seek and allow their voices heard. Sudanese culture as a whole is becoming more aware, inclusive, and accepting of children with disabilities.

These changing macro-level cultural factors are no doubt reflected in parents' and professionals' personal views about diagnosis and intervention.

The findings of the study indicate that ICT could be potentially helpful in Sudan and that there is a need for such tools given the current scarcity of other resources. However, this study has several limitations. Generalizability of this study is limited because of the small sample size. Despite this study's limited scope and generalizability, findings from this study can be utilized to raise awareness and understanding about ASD in Sudan among parents, professionals, and the larger society, and call to attention the need for more services and resources in local communities.

The findings of this study offer specific information regarding the exact needs of individuals with autism in Sudan. Parents specifically expressed a need for specialized education, more cost-effective treatments, more availability of therapy, early screening tools and more resources for older children and adults with autism. This study also offers valuable information about the gap in knowledge that may help in developing and implementing interventions that are sensitive to the needs of the child and their family, and consequently, contribute to an improvement in treatment outcomes for children with

disabilities. The study's utilization of qualitative methodology allowed the researcher to gather data that is rich in detail and embedded within the surrounding context. This helped to increase our understanding of the Sudanese parent and the lack of professional services currently in Sudan. Findings from this study are only the first look at the experiences and expectations for families raising a child with ASD in Sudan. One of the pivotal themes that emerged from this study was that, despite being members of the same broad cultural group and sharing many of the same traditions and practices, parents of children with ASD have different views about a child's disability. These views influenced how they perceived and understood a child's disability and shaped their beliefs and practices in terms of providing appropriate care for the child. Specifically, for parents in this study, their child's autism was an intensely personal experience that affected their lives and their families every single day.

One notable finding was participant interaction and appreciation to Dr Tamador's live video on Facebook. This demonstrates the willingness of parents to take advantage of the limited available resources. This also suggests that information through the Facebook platform is well-received, reinforcing that ICT could be quite impactful if implemented. Additionally, some mothers of children with autism created closed WhatsApp groups and are gathering once a month to share experience and knowledge. The groups were made possible by connections first made through Facebook. This is similar to the Facebook closed groups that protect the privacy of parents and create a means for parents to vent and share experience. Again, the immense participation through shares and views shows that there is a large population utilizing current resources and in need of more resources. The theme of privacy in support groups is also worth mentioning. This indicates that

parents desire privacy and ICT would allow further access to information while maintaining privacy.

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