

Telehealth services for rural areas in Saudi Arabia.

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Abstract

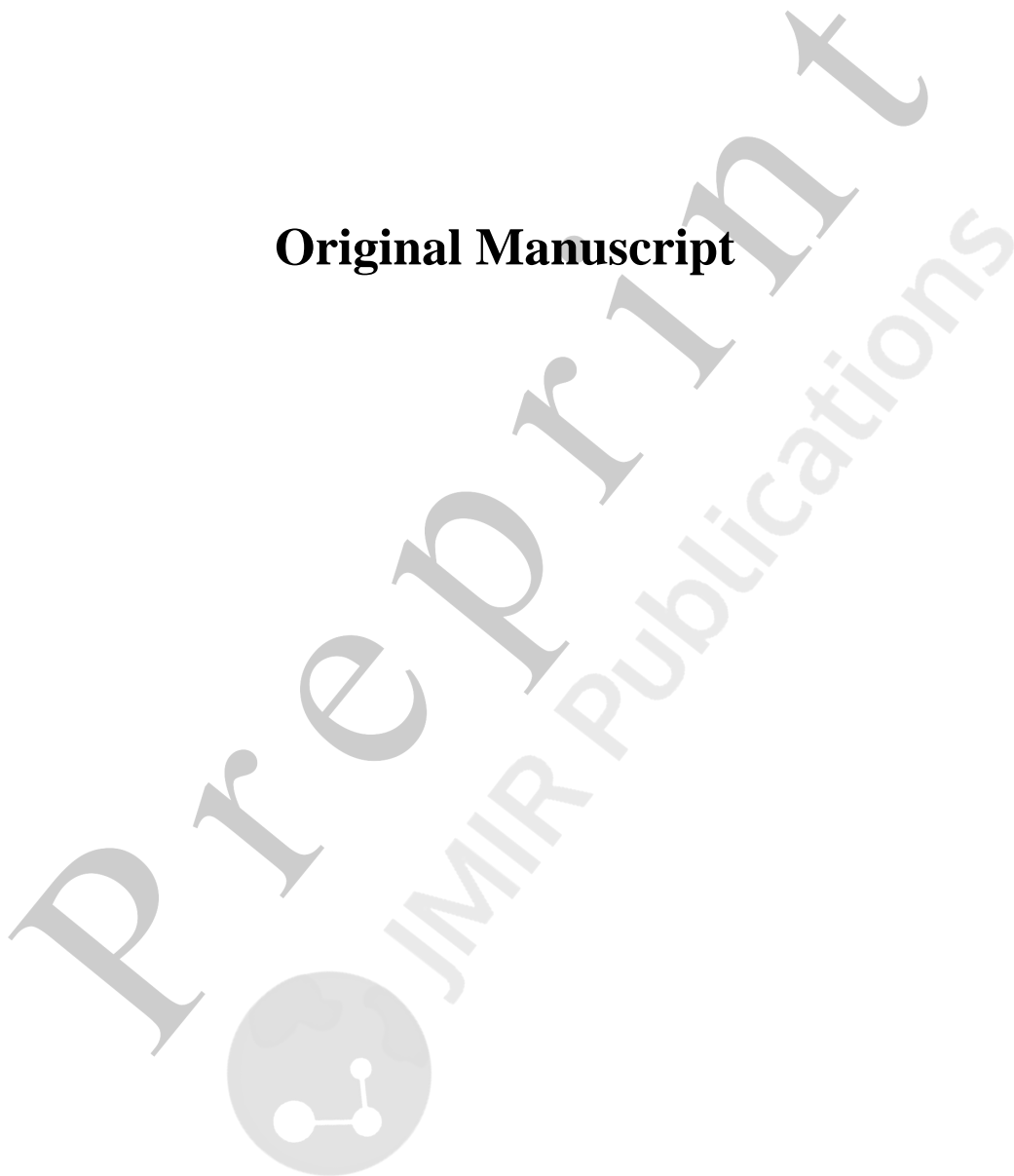
Autism spectrum disorders [ASD] are the most prevalent neurodevelopmental disorders nowadays. However, each child diagnosed with ASD presents a unique range of behavioral, communication problems, and issues with social skills. Many studies underline the importance of early interventions in helping both children with ASD to improve their skills and to provide their families with the necessary support. Despite this research, however, in Saudi Arabia, the earliest intervention that a child with ASD receives, in the major cities, is at the age of four due to limited services and a lack of awareness of the importance and benefits of early interventions. Families who live in rural areas of SA arguably have an even greater need for these services, as currently, they have to travel to cities, such as Riyadh, if they wish to seek help. Using telehealth services has been suggested as a particularly effective ASD intervention method for children who live in rural areas since it uses technology to provide consultations, interventions, diagnosis, training, and education. In fact, research indicates that telehealth services are as valuable as traditional face-to-face treatment, allowing families to obtain support from their homes and helping them to improve their quality of life. This review will discuss the application of telehealth services to support families in rural areas of SA in dealing with issues surrounding ASD, taking into account the cultural and religious context. Finally, it will examine ways that technology could be employed that would be suitable for SA's culture and needs.

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Telehealth services for rural areas in Kingdom of Saudi Arabia

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Abstract

Autism spectrum disorders [ASD] are the most prevalent neurodevelopmental disorders nowadays. However, each child diagnosed with ASD presents a unique range of behavioral, communication problems, and issues with social skills. Many studies underline the importance of early interventions in helping both children with ASD to improve their skills and to provide their families with the necessary support. Despite this research, however, in the Kingdom of Saudi Arabia [KSA], the earliest intervention that a child with ASD receives, in the major cities, is at the age of four due to limited services and a lack of awareness of the importance and benefits of early interventions. Families who live in rural areas of KSA arguably have an even greater need for these services, as currently, they have to travel to cities, such as Riyadh, if they wish to seek help. Using telehealth services has been suggested as a particularly effective ASD intervention method for children who live in rural areas since it uses technology to provide consultations, interventions, diagnosis, training, and education. In fact, research indicates that telehealth services are as valuable as traditional face-to-face treatment, allowing families to obtain support from their homes and helping them to improve their quality of life. This review will discuss the application of telehealth services to support families in rural areas of KSA in dealing with issues surrounding ASD, taking into account the cultural and religious context. Finally, it will examine ways that technology could be employed that would be suitable for KSA's culture and needs.

Keywords: Telehealth; intervention; Saudi Arabia; Autism spectrum disorders

Introduction

Autism Spectrum Disorder [ASD] is the most widespread of all developmental disabilities: global figures have dramatically increased since the 1980s when they were estimated at a rate of 1 in 10,000, to a figure of 1 in 68 in 2016 [1]. In the Kingdom of Saudi Arabia [KSA], however, there is no data about the number of cases of ASD, although it is estimated to be over 167,000 in a population of over 28 million [2]. Yet, currently, the services available for children with ASD in the cities do not meet the demand, and as a result, some families are forced to travel to neighbouring countries [e.g., Jordan] and/or overseas [e.g., United States of America] for services [2]. While the rest of the world are continually developing ways to improve intervention methods to ensure better lives for children with ASD and their families [3], KSA is still lagging significantly behind [4]. This is because methods developed in the West are not always culturally suitable for KSA, particularly in relation to their prescribed gender roles [1]. However, one method that might be effective is telehealth services. In this view point, we will consider the evidence that using telehealth to provide services to ASD children is effective, reviewing studies conducted outside KSA. Therefore, we will also discuss the potential applications of this method to the Saudi context, and the challenges it may carry, in particular due to cultural specificities, and also providing recommendations to overcome these barriers. To build this view point, we conducted a narrative literature review, as this is a useful method to develop recommendations for clinical practice [5]. Literature was identified through an electronic keyword search across four databases (PubMed, Web of Science, CINAHL, Scopus) using the terms 'telehealth', 'family-centred approach' or 'technology', always in combination with the term 'autism' (using the AND Boolean term), and dated up to April 2017. The search terms were selected for their relevance to the research question, and kept broad to try and reduce selection bias. However, the search was confined to peer-reviewed papers, as the literature review was not systematic; additionally, unpublished

and grey literature was not considered relevant to inform clinical practice, due to its lower standard of evidence.

Telehealth services for children with Autism Spectrum Disorders

The most evidence-based intervention for children with autism is early behaviour intervention [6], which also presents the advantage that it can be delivered by anyone with training, not only practitioners with advance degrees (such as clinical psychologists or therapists). In early behaviour intervention, therefore, even caregivers are practitioners, as long as they have received training. Additionally, using a Family-Centred approach to educate and support caregivers of children with ASD has been found to improve outcomes for children [7]. In this approach, the caregivers' needs are also taken into account and caregivers are trained to interact with the child with ASD without therapists assuming what caregivers know [8]. Russa, Matthews and Owen-DeSchryver [9] stressed that ASD interventions are interdependent on caregivers, and that their active engagement is key to positive outcomes. However, delivering early behaviour intervention and family-centred services face-to-face encounters many barriers, such as the scarcity of trained therapists, limited resources and services, the low socioeconomic status of many families, lengthy waiting lists, and practical issues arising from the fact that these limited services are only available in major cities [10]. It is vital, therefore, to investigate how caregivers can be helped to transition and adapt to new ways in which interventions for ASD can be provided [10]. Due to the significant increase in the use of the computer and internet in everyday life, telehealth services, which use technology to provide services from a distance to families with a child with ASD, could be an alternative and effective method of providing support [10]. This method presents a number of advantages. Firstly, the possible advantage is that the family can interact directly via a video with an instructor, which means that

they potentially have access to a greater range of expert therapists. Secondly, telehealth technology, through providing caregivers with an opportunity to take an even more active role in their child's development, would empower them and accelerate the diagnostic process [10,11].

Telehealth consists of a range of computerized software applications, such as video conferencing, DVDs, 3D interactive programmes, phone applications, and telephone and web-based tutorials [12]. Studies of telehealth-based parent training document that the caregivers found the training programmes to be convenient, practical, appropriate and helpful in increasing their knowledge about evidence-based intervention methods [13-15]. Studies have also documented positive changes in children's outcomes [3,10,11,16]. For instance, a study with North American families with ASD children below 48 months revealed that teaching parents the Early Start Denver Model intervention through videoconferencing and a website resulted in increased rates of vocalization and joint attention initiation in the children [3]. Similarly, a study with 24-72-month-old children with ASD in North America found that teaching parents an imitation intervention through remote coaching and self-directed online study led to increases in spontaneous imitation in the children [10]. However, it should be noted that most of the studies have been done with very small to small samples; the only study with a reasonable sample size [13] did not measure children's outcomes, and implemented the training not only with caregivers but also professionals working with children with ASD (e.g., teacher assistants). A further limitation is that all studies included mostly college-educated participants, while the principles of early behaviour intervention are that it can be implemented even if ones does not have an advance degree [13]. This last limitation will be particularly discussed in the context of KSA.

Barriers and challenges in adopting Saudi telehealth services for ASD children

In KSA, families of children with ASD, particularly those living in rural areas, currently encounter many difficulties when seeking support [4]. As mentioned earlier, the number of children with ASD is rising, but services are

only available in major cities, and due to limited resources, waiting times for appointments or family-centred approach sessions can take between 8 and 12 weeks [17]. In addition, the costs of travel and the service itself, and the need to juggle receiving support for their child while keeping jobs and meeting other responsibilities, all put a significant strain on families living in rural areas of KSA [2,17,18]. For such families, telehealth would seem to address many of these issues and provide additional support to existing services. Telehealth services could be used as a tool for teaching strategies to improve the outcomes of children with ASD and their families [17,19]. However, the cultural context and the beliefs, educational levels and socioeconomic status of the KSA population need to be considered when selecting appropriate methods of intervention [18]. Besides, because this method employs technology in a new way, research is necessary to identify a reliable, evidence-based telehealth framework and intervention programme for delivering services at a distance in Saudi culture.

The first issue to take into account is that in KSA culture women assume the role of homemaker and carer while the men provide for and protect the family, leaving the mothers with almost the complete responsibility for taking care of the children [20]. In addition, KSA culture dictates that males and females be always separated [e.g., education, banking, and health], that females are required to cover their faces in front of males, and some of them are not allowed to have their picture taken [20]. This all makes communication between genders a sensitive issue [21]. In fact, face-to-face contact between men and women is prohibited by culture, and this includes online communication [21]. Therefore, as Alqahtani [22] reports, this means that in some cases, interventions or interviews with mothers of children with ASD are not allowed to be conducted by men without her relatives being present. This reduces the opportunities for teleconference or video conferencing sessions that are based on face-to-face sessions between the therapist and the mother, which could help the therapist to provide recommendations, answering questions and giving an intervention strategy while observing the child through the camera in their own home [23].

A second obstacle to using technology to provide assistance to families affected by ASD is the prerequisite that they: [a] have a computer or a phone

that can access the internet, [b] have a high-speed internet connection, and [c] are IT literate [19]. Although 40% of KSA families living in rural areas are living below the breadline [24], by 2012, 95% of Saudi individuals had a mobile phone, and mobile internet penetration was of 70% [25]. In other words, it is less and less likely that parents of children with ASD do not have access to the internet in some form, or at least to a phone.

Using telehealth programmes to assist families with a child with ASD would require training [19] and, as highlighted earlier, so far studies that tested telehealth effectiveness in the context of ASD mostly recruited educated participants. However, KSA has poor educational levels [18]. In fact, in rural areas, many mothers of children with ASD do not have a degree and have often not attended high school [18]; some of them are even illiterate, which makes using technology extremely difficult [2,18,22]. In addition, the Saudi government does not provide much education on how to use technology and as a result, institutions, such as public schools in the rural area, are often not aware of the latest advances in technology [24].

A third problem with implementing a telehealth service in KSA is the need for Saudi mothers, as the principal carers, to talk to female rather than male therapists [27]. However, despite the fact that the health system is one area in which allows a mix of genders in KSA, this is a male-dominated field, with a low number of Saudi females working in it [20,28]. This means that the majority of female professionals in the KSA healthcare system are foreign workers, which often results in problems with the delivery of information because a translator, who is more often than not a non-expert, is needed [20,28]. In addition, many online applications are non-Arabic, and therefore a team is required to translate the applications into Arabic. Yet, as mentioned above, Saudi expertise in technology is limited [28].

Finally, using telehealth services requires the caregivers to be their child's ASD therapists, taking on board new strategies for care, and using different technological methods of intervention from the professionals [10]. However, Saudi families [especially mothers] have historically placed a profound trust on healthcare professionals which might result in them not wanting to take on such an influential role in their child's intervention without a healthcare team [29].

To sum up, introducing technology to support families living with ASD in rural areas clearly has many advantages, not least of which is its flexibility. However, KSA is a traditional country where Islamic teachings and Arabic cultural values are strictly followed which means that such telehealth services need to be selected and implemented carefully. Cultural factors such as the need to hire both male and female Arabic-speaking educators, gender roles, and educational levels all need to be taken into consideration.

Recommendations for Best Practice

Using telehealth services is new in KSA, and many of the barriers mentioned above could prove detrimental to the success of this service. However, there is a clear need to help families with children with ASD living in rural areas [4]. Nowadays, the world revolves around technology, and it enhances social interaction through its convenience, facilitates knowledge-sharing among not only health professionals and those living with ASD but also the broader community, and will lead to positive change in the health sector (e.g., through treatment plans) [29]. For example, the use of mobile internet technology has shown promising results in allowing interventions to reduce stress in Saudi parents of children with ASD using WhatsApp [26].

Given the up to date evidence the government and the health minister now need to implement and explore assisting families affected by ASD through the use of technology, engaging both genders in the use of computers and up-to-date software. Furthermore, increasing socialization between genders and explaining that this change might benefit children with ASD could positively impact on the development of the child and the families through the improved access to quality medical and behavioural services in the healthcare system [4]. However, it is acknowledged that occasionally, the distribution of physical training materials (e.g., printed manuals) may, for the time being, be required to educate those in rural areas without internet access. Nonetheless, not all rural regions of KSA lack access to the internet, and as highlighted earlier, mobile phone ownership is now widespread, with a large mobile internet penetration [25]; it would therefore be of value to consider telehealth services for such regions.

Indeed, many Saudi caregivers reported to Alqahtani [22] that their

children were diagnosed with autism at the age of seven because the hospitals in their area were not trained sufficiently to diagnosis autism. They had to refer the children to significant cities for diagnosis, which then took months because of the limited number of professionals who could diagnose the disorder. Delay in diagnosis can lead to delay in early intervention services despite the evidence that early year intervention improves children's outcomes [29,30]. In this regard, NODA SmartCapture, a mobile phone-based application for caregivers to record several video evidence of their child's behavior in their natural environment (e.g., the home) could support diagnosticians in finalizing the diagnostic assessment of ASD [11]. Using NODA, caregivers are asked to put the child in specific social scenarios, to ensure the recorded videos provide professionals with the necessary elements to make a diagnosis. Therefore, the scenarios were built around the DSM-V criteria [31]. Preliminary research found a 91% agreement rate for diagnoses done over NODA vs diagnoses done previously face-to-face (by another professional) [11].

This method presents with specific advantages for rural populations. Firstly, the fact that families do not need to purchase relatively expensive equipment and no longer pay travel expenses makes it cost-effective and, therefore, a much more attractive option [10, 11]. In addition, for the family of a child with ASD, who may dislike change to their routine and social context, no longer having to travel to vast, anonymous cities is clearly a significant benefit regarding the reduction in stress [10]. Additionally, online assessment through videos would be more ecological as the child would be in their natural environment. While it may be argued that online assessments may lack reliability, Smith et al. [33] reported similar results between online and face-to-face clinician assessments in a prospective study of 50 families (88.2% agreement). Furthermore, 95% caregivers reported that NODA SmartCapture was easy to use and were able to record videos in their homes successfully [32]. Therefore, NODA SmartCapture could improve the efficiency of the diagnostic process for ASD in KSA.

However, internet access is uneven in rural areas of KSA, and the advantages of NODA could be reduced. Professionals should therefore consider the use of telephone services to conduct diagnosis, as a fall-back option [16],

since 95% of the population is believed to own a mobile phone [25]. Professionals could administer the Autism Diagnostic Interview-Revised [ADI-R] via the telephone [35]. The ADI-R is the gold standard for diagnosing ASD, and, as for NODA, research carried out into diagnoses made by ADI-R showed that there is no significant difference between face-to-face interviews and those undertaken over the phone [35]. Once an ASD diagnosis has been established, we currently would recommend that the family is invited in a major city for further assessment (e.g., intellectual), as there is currently only little evidence that these could be done via telehealth for ASD, and only with young adults [36]. While it is still inconvenient that those receiving a diagnosis remotely will need to travel to a major city regardless, for intellectual assessment, this will still minimize the number, and thus cost, of trips, and therefore may be able to reduce the average age at which those in rural areas receive diagnoses, thereby facilitating early interventions. Once the full assessment conducted, the aim is to provide further support regarding interventions through telehealth (and occasionally printed materials), which will also reduce further the number for trips needed. Moreover, remote consultations could minimise the burden on hospitals in major cities by identifying those whose behaviours are not symptomatic of ASD and who, therefore, need not receive an in-person consultation.

Secondly, web-based learning is a method that could be of immense help to the families of children with ASD after diagnosis; it could potentially contain video tutorials which highlight specific ASD behaviours and advise caregivers of how to use intervention strategies correctly [37]. In KSA using web-based learning is, in theory, both extremely valuable and flexible in that it can be adapted to suit the cultural context of families of children with ASD [37]. In addition, in KSA, while male therapist cannot train female caregivers face-to-face about behaviours of children with ASD, it would be acceptable for women to watch learning videos by male therapists, as this does not represent direct contact. This is an additional advantage of telehealth in the Saudi context: not only using learning videos can allow therapists to train a wider population, outside the major cities, but it allows not to rely only on female trainers, which would be necessary if delivering face-to-face training to female caregivers.

Therefore, for Saudi female caregivers who cannot read or understand medical terms, such videos would be immensely useful. The website could also have a forum either using or similar to, email, so that caregivers can send and receive messages either by voice message or text to their therapist, who could then provide relatively instantaneous advice and support [3]. Since the Saudi culture is strict about communication between genders, it is suggested that the forums would be moderated by female staff, through whom communication between female caregivers and male therapists could occur.

Another method would be to develop a website that provides caregivers, and the general public, with resources, such as information on autism symptoms, educational brochures, early interventions programmes, strategies for dealing with issues at home, community activities, and local events [3]. Besides, it should allow the caregivers to post anonymous conversational topics, as suggested earlier, tips, and progress updates about their child—or any other information they want to share [3]. In KSA, such a method could help in solving the separation issue between the genders, helping them to support each other and increase their awareness of other local families of children with ASD, keeping them up-to-date on new interventions for ASD. This would also help raising public awareness of ASD symptoms [22], increasing chances that caregivers seek treatment early, including in rural areas. As mentioned earlier, it was found that online training for families of children with ASD were equally as effective as face-to-face workshops [38].

A further point to mention is the benefit that telehealth services could also bring to health professionals. Alqahtani [22] stated that many ASD therapists in KSA are not trained in the latest intervention strategies, and therefore, web-based learning could help them stay up-to-date on the latest research and intervention techniques [16]. For example, a preliminary study by Vismara et al. [38], including ten therapists, explained that training therapists via telehealth to use the Early Start Denver Mode for ASD was particularly effective, and Hamad et al. [13] found that a larger sample was able to improve knowledge about early behaviour intervention significantly after e-learning.

Finally, a few different interventions have been tested through telehealth in recent years [see 39 for a recent review]. In most studies, outcomes were

positive [37,39], suggesting that telehealth could be applied to most interventions currently in practice. An examination of these studies indicates that providing caregivers with online coaching is conducive to achieving optimal outcomes. For instance, Ingersoll and Berger [40] found that parents of young children (27-73 months) were more likely to engage with a social communication intervention (ImPACT Online) if, in addition to completing online lessons, they participated in 30-minute videoconferences with therapists twice per week, compared to parents who only completed the online lessons. Engagement was, nevertheless, high in the group that only engaged in the lessons, which consisted of a range of media, including slideshows, videos, quizzes, and reflective questions. Similarly, Pickard et al. [41] observed that, in comparison to parents who completed self-directed online study, parents who also received online coaching via Skype were more likely to report improvements in communication in their 19-73-month-old children. Lindgren et al. [42] report that telehealth teaching of functional communication training that is delivered in the caregiver's home is as effective as telehealth that is delivered in a regional clinic and as effective as in-home therapy with respect to reducing problematic behaviours in 21-48-month-old children. Home-based telehealth, however, is the most affordable of these approaches. Taken together, these results suggest that online web-based lessons that use a range of media represent an effective and comparatively cost-effective method of improving outcomes in children with ASD, and that their efficacy might be enhanced by online coaching. However, further research is needed to compare directly telehealth interventions, so that the most effective can be recommended; this is all the more important considering the known issue of publication bias, through which results less favourable to telehealth might not be published [39,43].

Conclusion

Autism is becoming increasingly recognized as a disorder in KSA, yet there are limited services in rural areas. Increased public awareness about the disorder is needed to meet the demand for adequate services, support, and research suitable for the Saudi cultural context. While services and support can

be found in major cities, this is not representative of the whole country. Alternative methods for assisting families dealing with ASD can potentially be found through technology. Clearly, however, the use of technology faces many obstacles due to KSA's culture and religion; but by adapting it accordingly, it could make a significant difference to the lives of those families with ASD children. Further, not only could healthcare professionals in KSA interact with caregivers in rural areas, providing consultations, behavioural interventions, and other support, but using such methods may also lead to more acceptance of the use of technology in society in general. However, for this progressive, yet effective method of support to gain momentum in KSA, research about its implementation needs to be undertaken as a matter of priority.

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