

Investigating the Use of Social Media Technologies by Adults with Autism Spectrum Disorder in Saudi Arabia

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Abstract. People diagnosed with Autism spectrum disorder (ASD) face difficulties in everyday life with their communication and interaction skills. Previous studies have shown that the use of social networks could be used by people with ASD to help them build connections and overcome their difficulties with social skills. However, most autism intervention research has involved young children in Western cultures. In Arab countries, adults on the autism spectrum experience the same difficulties in addition to dealing with other issues, such as stigma within society, a lack of services, cultural rules and the inability to sufficiently benefit from existing technologies designed according to the culture and language of Western countries. This study focuses on exploring and observing the use of social media by people with ASD (high-functioning autism and Asperger syndrome) in Saudi Arabia. The aim of this research is to understand the role that technology plays in the lives of adults with ASD in Saudi Arabia, in order to make recommendations for research and practice. This research could also help future researchers to understand the needs and behaviours of Arab individuals with ASD towards social technologies, and it could be a leading research for the autism community in Arab countries.

Keywords: Social media · Technology · Accessibility · Usability · Communication · Social skills · Culture · Arabs · Adults · Autism

1 Introduction

Autism spectrum disorder (ASD) is a lifelong developmental disability. People with ASD face difficulties with social communication and interaction and restricted repetitive patterns of behaviour, interests or activities [1]. A high number of adults with ASD experience difficulties with face-to-face communication and may try to avoid social interaction and group activities [2]. By working on finding ways to support communication in more comfortable and less threatening ways, people with ASD may have a better chance to be employed, be in a relationship, have friends, increase independence, have a better life and be part of the community [3].

The original version of this chapter was revised: In Table 1 on page 229 of the original version of the paper the last 5 rows were missing. The erratum to this chapter is available at [10.1007/978-3-319-40238-3_62](https://doi.org/10.1007/978-3-319-40238-3_62)

It has been claimed that computer-mediated communication (CMC), such as emails, blogs, online social networks and text messaging, for social support are ideal methods for individuals with ASD because they provide the user with some control over the conversation as well as more processing time [3, 4]. However, adults on the autism spectrum receive much less research attention compared to children, and most autism intervention research has involved young children mostly in Western cultures [5, 6]. Consequently, there is very little research regarding the experiences and preferences of adults with ASD regarding technology use, and almost no research about this topic in non-Western countries.

In addition, people with ASD have difficulties understanding unwritten social rules and cues in their daily lives [2, 7]. Several studies have shown a positive impact of social technologies on individuals with ASD within the Western culture [8], however, Arabic cultures have a different set of beliefs and social, religious, moral and political rules and restrictions that are carried from the lives of people offline to the online world and could affect the behaviour of such users when using an online system [9, 10]. In Arab countries, less research generally has been carried out regarding ASD [11], and research focusing on the use of social networks by people with ASD who are Arabs and who live within the Arabic culture has not been investigated before. These issues demonstrate the importance of implementing a study considering investigating the role of technology in the lives of people with ASD in Arab countries. This study will discuss the use of social media by the participants, how and why they are using different social networks, what challenges they are facing in regards to their culture or their social skills, and what benefits they feel the social networking sites bring to them.

2 Related Work

Social Media for ASD. Social networking sites (SNS) have been very popular in the past few years, and a large number of people are connecting via these networks, with around 29 % active users of the world's population in 2015 [12]. These communication technologies can have a potential impact on people's communication, socialising and learning [13]; it is a type of human-human interaction rather than just a computer-human interaction [14]. Social networks provide users with the ability to connect and socialise without the pressure of time and immediacy that they face in real-life social situations. It has also been reported by [15] that adults and adolescents who are not confident socially prefer to communicate online because they feel more comfortable and less shy than when communicating face-to-face, as stated in [8]. Also, according to several studies, communicating via online social media has been beneficial for socially anxious individuals, providing the ability to increase the quality of friendships, enhance engagement and decrease loneliness, which raised the issue that social media could be relevant and well-suited for adults with ASD as well [8].

Recognising these potential benefits, some social networks have been designed for people with ASD and their caregivers for sharing information, improving their awareness and capacity to communicate in a safe space, such as MyAutismTeam by [16] and Squag by Sara Winter [17]. However, these social networks are specially designed for

children and do not focus on improving their ability to connect, socialise and be independent. Supportive Eyes, or *Miradas de Apoyo* is a social network that enables users to organise groups to provide support for any individual who needs it, such as someone with ASD [18]. In 2014, a social network “Connect” was created by Autism West Midlands. The social network is a supportive network, which was designed to help people with autism in the UK and their families to meet new people and find friends [19].

Other studies have used social networks to help individuals with ASD build independence. A study by [20] considered the use of a supportive social network aiming to provide young adults and adolescents with Asperger syndrome with the opportunity to gain support from a group of family and friends instead of over-relying on one caregiver. The idea was to use circles (a feature in social networks that brings together a group of people interested in a particular topic or people with a common social connection) to seek information and advice and to build independence [20]. In addition, another study integrated a supportive social network into a mirror implemented by the Graphics, Visualization & Usability Centre in Georgia. The design is called the SocialMirror; the aim was to help adults with ASD to be more independent by providing them on-demand support and to learn daily life skills, based on an idea similar to prompting systems [21]. These two projects used private social networks and involved family and friends to provide support for the individuals with ASD. Parental communication and their involvement in online activities of persons with ASD showed that it could reduce the effect of cyber victimisation and provide higher levels of self-esteem [22, 23].

Independence and autonomy are important for an individual with a disability, but the concept differs between cultures [24]. In most Arab countries, the culture prevents single individuals from moving out of their family homes unless there are specific reasons, so the chance of moving out is less than in other countries, especially for women [25]. Although this is a dated reference now, this situation still remains the case in Saudi Arabia. Therefore, technologies that seek to promote autonomy and independence developed in Western countries may be of much less relevance to people with ASD in Arab countries.

People with ASD tend to have less understanding of sexual behaviours, lack judgment, are socially naive and have difficulties with social awareness [26]. In addition, it was found that people with intellectual disabilities could be more vulnerable socially than others [27]. For example, in Arab countries some female users are strict about using their real names, adding their photos or adding videos of themselves in general online social networks [28]. They could use nicknames or drop their last name, and add comic or other type of images as their profile photo on Facebook to cope with the restrictions they could face [29]. This could increase the chance of being tricked by people with fake identities. For Arab users with ASD, conservatism and privacy could be one of the factors that affect the use of social networking technologies. It could cause ambiguity in online dating, chats or any other type of online social networks.

In addition, in regards to communicating and building friendships, in some Arab countries, the situation is more difficult with more cultural communication restrictions, as communicating with the opposite gender is already an issue with many people [30]. Also, awareness of ASD in these countries is limited [31], and families are more likely to hide their diagnosed children to prevent themselves from feeling shame and to protect

themselves from harsh societal judgments, which could increase the social isolation of people with ASD [32]. However, the use of such social networks by adults with ASD may have a different implication as they are less aware of the social restriction and social cues [7], and yet this has not previously been explored in research. Therefore, this current research focuses on finding out what technology devices adult Arabs with ASD are using, how they are using social networks and for what, nature of their online relationships and communication, and the effect of online social networks on their lives.

Technologies for ASD in Arab Countries. In regards to Arab adults with ASD and the use of social networks, no Arabic social networks specifically designed for people with ASD exist, nor do any support the Arabic language. Although adults with ASD can use the more popular social networks, such as Facebook, Twitter and MySpace, the use of social networks has not been studied for Arabs with ASD.

Only a few studies regarding the use of technology among people with ASD in Arab countries were found in a literature search. A study [33] was conducted a study on the development of a multimedia environment for teaching vocalisation to children with autism. The goal of the project was to help the children with their communication skills [33]. However, it has been reported that the development of the system is still in process and has not been completed. In [34] a portable and configurable augmentative and alternative communication (AAC) tool for Arabic-speaking users called “Touch-to-Speak”, which was aimed to support people with speech and language impairments in carrying out their daily conversations was introduced. It works by translating a series of pictures into well-structured Arabic sentences; it supports Modern Standard Arabic (MSA), in addition to various local Arabic dialects. However, the target users of the tool are children with ASD and elderly people following a stroke, so it may not be very useful for adults with high-functioning autism or Asperger syndrome. In addition, a study of an Arabic app called “Talk the Talk”, designed by Fatani and Mashat for teaching conversational skills to children with ASD, was reported in the *Al-Watan* online newspaper as the first Arabic app in this field [35]. The implementation of the app has not been yet completed; therefore it is not evaluated or reported in a peer-reviewed literature.

However, other AAC applications such as “Tap to Talk” and “LetMeTalk” are available in Arabic language, but are mainly designed for children [36, 37]. Consequently, there remains a substantial gap in knowledge with regard to whether and how adult Arabs with ASD are using online social networks in their daily lives.

3 Research Method

People with ASD are not all the same, and there is limited information about the people with ASD in Saudi Arabia. In order to seek in depth information about the participants, face-to-face interviews were implemented.

Reaching individuals with ASD and recruiting them for the study was extremely challenging. This could be because in Arab countries individuals with ASD might be hidden, not diagnosed or do not admit the disability [32]. Nevertheless, participants were eventually reached via ‘snowballing’ or ‘chain sampling’ techniques [38], in addition

to an online recruitment survey addressed to the caregivers. In total, 13 adults/adolescents with ASD in Saudi Arabia have been interviewed.

The interview was focused on investigating the use of social networks by adults with ASD and exploring the impact of cultural factors, on their usability and sociability of social media. These factors were identified previously as a “Framework for Autistic Arab’s Social Communication and Interaction Technology” FAASCIT) [39], suggesting that these factors might have an influence on Arab users when it comes to using social media technologies. Some of the factors are cultural or tradition factors, related to the people themselves or to the social rules in Arab countries, and other factors could be considered as technical such as language, Internet access, gender differences, photographs, communication with the opposite gender, privacy, conservatism, autonomy, relationships and music.

The structure of the interview was designed in different sections, and the questions were semi-structured. For example, participants were asked some personal questions such as their age, occupation, what devices they own and what social media applications they use. They were also asked to connect to the Internet and to open a social network they are using, in order to observe their ability of accessing their own social networks’ accounts. In addition, questions were asked about the language they prefer using, the information they display online, the number of friends they follow or have, their communication with family and friends and the main things they do on social networks. Also, participants were asked to read some sentences in English and also sentences written in Arabizi, which is Arabic language written with Latin letters [40]. The questions were in general directed for the participants, but the caregivers could be involved during the interview also.

Ten of the participants were males and three were female, all from Saudi Arabia: two from Al-Hasa, three from Makkah and eight from Jeddah, all of whom are known to be diagnosed with ASD. One participant from Riyadh initially agreed to take part but withdrew before the interview. The participants are coded with (P1, P2...Pb13), where P1, P2, P3 and P4 are the eligible participants who were reached from the online survey, and Pbn, n(5-13) are the participants who were reached during the interview stage by personal contacts. The interviews were audio recorded and were all conducted in Arabic apart from the interview with Pb10, which was conducted in English. Information collected from the participants are saved securely and all data are anonymised.

4 Findings

The study initially aimed to include participants with high-functioning autism or Asperger syndrome, however, due to the recruitment difficulties not all participants were high functioning. Due to the differences in the level of functioning, only seven of the participants (P1, P2, P3, P4, Pb5, Pb10 and Pb13) were able to contribute during the interview, one of whom was female, see Table 1. The other participants had less advanced verbal abilities, and the caregivers were interviewed instead. However, P2, P3, P4, Pb5, Pb10 and Pb13 were the participants who were using social media. Currently, P1, P3 and Pb5 are working, P2 is going to college, and P4, Pb10 and Pb13

are attending mainstream schools. Pb7, Pb9 and Pb12 still go to autism centres, whereas Pb6, Pb8 and Pb11 had to stop attending the centre at a certain age and now are staying at home.

Table 1. Participants' uses of social media

Participant	Gender	Age	Devices	Used SN	Created SN for the study
P1	Male	30	Ipad (shared with his sister)	None	Instagram
P2	Male	23	Smartphone ipad PC Laptop	WhatsApp, (Facebook and Twitter, could not access it)	Instagram
P3	Male	22	Smartphone Galaxy 5S laptop (broken)	WhatsApp, Snapchat	Instagram
P4	Male	19	iphone 5S	WhatsApp, Snapchat, Instagram Facebook, Twitter, Keek, Path, BB messenger	None
Pb5	Male	23	ipad 2	WhatsApp	None
Pb6	Male	16	ipod	None	None
Pb7	Male	25	Galaxy smartphone and uses his sister's iphone 6	None	None
Pb8	Female	19	ipad 2	None	None
Pb9	Female	15	Does not have her own device	None	None
Pb10	Female	15	xbox, playstation3, playstation4, ipod, iphone, wii, wii U, PC, laptop, Graphic drawing tablet	YouTube, Tumbler	None
Pb11	Male	28	Samsung Galaxy smartphone, Toshiba Laptop	None	Instagram
Pb12	Male	15	Does not have his own device	None	None
Pb13	Male	18	Lenovo Smartphone, Tablet (being repaired)	WhatsApp, (Instagram and Facebook, could not access it)	None

The Use of Social Media. In regards to the six participants who used social media (P2, P3, P4, Pb5, Pb10 and Pb13), P2 said he has a Facebook account, but he prefers using Twitter. He could not access Facebook as he could not remember his username and password. His mother did not know about the Facebook account and she said he might

have created an account lately. He opened his Twitter account, but then it appeared that the Twitter account was not his account, but rather his sister's account, which was opened on his iPad. He uses WhatsApp for chatting (with his family and uncles), and has a family group of 5 people who are his close family. He chats with his friends with direct messages on WhatsApp for college work. His mother said only the people who might have a good influence on him or add some useful knowledge to him are the people who are allowed to chat with him. She does not want him to waste time with people on WhatsApp or chat with people who might tease him or make jokes out of his mistakes. She was asked to create an Instagram account for him in order to be able to watch his activities and interactions. She created the account for him but he has not been using it.

P3 is using WhatsApp and Snapchat. After having Instagram and Facebook explained to him, he was asked if he would like to create a Facebook account but he said "no". He agreed to create an Instagram account. After he had created it, he got excited and asked to create a Facebook account. The Internet connection was not good enough and he had to go upstairs every time he needed to download something. He could not download Facebook and he became disappointed and did not want to do it. He was happy to use the Instagram account, but has only used it on the day of the interview when he created it and a few times afterwards with limited activities.

P4 uses Facebook, Instagram, Snapchat, Keek, Blackberry messenger, Twitter and Path. He uses Instagram, Snapchat and Path the most. He is active and has lots of online friends. He uses Snapchat to post comedy snaps for entertaining people.

Pb5 was interviewed with his teacher at the centre. He uses WhatsApp daily and chats with his family and friends. With regard to creating an Instagram account for him, he had to ask his parents before setting up an account, and he does not yet have an email address. He was asked to get permission from his mother, but he did not ask and the teacher has not responded in this regard. He has been active on WhatsApp and is sending photos, mainly photos of money notes.

Pb10 has a channel on YouTube and she posts videos about her awkward life, as she says, and she is a new user on Tumblr. Watching the number of people who have viewed her videos or subscribed to her YouTube channel makes her excited. She likes drawing comics, and she started posting them on her blog. When she was asked about Facebook she said, "No, I don't like Facebook. I am more like a video fun person, Tumblr person". When she was asked about Instagram she said "I am not a cliché of the generation". Then she said she does not like Facebook because her spelling is not good and she is kind of dyslexic.

Pb13 has both Facebook and Instagram accounts. He only uses his smartphone at weekends. He could not remember the usernames for his accounts. On Facebook his account could not be found even with the given name and profile picture, and with the help of his caregivers, which could be a result of the privacy settings. The Instagram account was found once, after a while the account was not there anymore.

On the other hand, P1 has good verbal abilities, but he needs to be directed and taught how to use social networks. P11 has less verbal abilities, but his mother tried to help him and created an Instagram account for him. Instagram was chosen as it appeared to be preferred over Facebook, and it requires less information and steps for setting up an account and less functionality.

The other participants who are lower-functioning Pb6, Pb7, Pb8, Pb9 and Pb12 mainly watch YouTube cartoon songs, and tended to use fewer educational apps. This could also be due to the lack of Arabic applications and programs for people with ASD, but even the available Arabic apps such as “Talk to Talk” and “Touch to Speak” are not being used by these participants.

Friendship and Family Relations. Participants were asked about their friendships and relationships with others, in order to have an overview of how they communicate with their friends, and whether or not they have friends offline, and if they have any online contact with family and friends. In regards to P1, he does not use any online social networks, so he did not have any online communication, however, during the interview he was searching on Google and said he is looking for a girl to play with. He said, “I want a girl”.

P2 has friends on Facebook, he mentioned only male names. He said he has three friends on Facebook who are his friends from college. However, his mother and siblings are not friends with him on Facebook, as he mentioned. WhatsApp is used by the family more than other social media application, he have a family group on WhatsApp consisting of five members who are his parents and siblings, he also have contact with his uncles and his friends from college on WhatsApp in a private chat, but no contact with his cousins online.

P3 uses Snapchat to contact people by sending photos to them; he has about 50 contacts on Snapchat mainly his relatives, and he does not have any concerns about contacting his female relatives. He has only two of his friends on Snapchat, and he said he speaks with his friends when he meets them in person and not via Snapchat. On WhatsApp he also contact his family and relatives, he has WhatsApp chatting groups with his aunts from both of his parents sides.

P4 has 160 friends on Facebook, which he said they are relatives and friends, and on Instagram he has 1380 followers and is following 2301 people. He also has friends at school, but he said he only has one friend out of school. However, he might not know the people in the entire list in person, but he is communicating with his friends via social networks, mainly Instagram and Snapchat.

Participant Pb5 is working at the centre, which he used to go to. He still has his friends there and also he is still in contact with his old friends. He chats on WhatsApp with his cousins, and also with his friend P3, who was at the same centre he attended.

Pb10 is in a mainstream school, and she only has one friend at school, she talks with her in English. If she wants to speak with her out of school she just makes a normal phone call. She does not use any chatting social networks.

Pb13 is also at a mainstream school but he is in the class with only five other students. His stepbrother is also his friend and is always helping him at home. In the interview, he said he would like to have Skype to call his friend, who was his previous bus driver.

The participants who used social media were asked to be added by the researcher for online communication. None of the participants rejected, but only P3, P4, Pb5 have been staying in contact, and P3 with only limited communication. P1 has been followed on his new created Instagram account, but he does not know how to access it. P2 used a Twitter account to be in contact, which is his sister’s account. He also created an

Instagram account, which he never used. Participant Pb10 has been contacted via Tumblr, but she does not reply as she has started using it recently and might not be accessing it regularly. Whereas, Facebook and Instagram accounts for Pb13 were provided by the caregivers after the interview, but neither could be reached or found.

Cultural Differences in Technology Use. Cultural differences could appear in some particular situations, and also it could be different for different users. One of the main cultural aspects is language, limited English abilities had appeared for example, when asking P2 to sign in to his Facebook account, he entered “hotmel” instead of “hotmail”, this could prevent him from accessing his account, however, he had problems remembering his password and also accessing his email. Another example is with one of the caregivers, she is making her daughter learn from an app, which is in Spanish, when asking her “It is in Spanish, she said not its English”. However, the app has Portuguese, Spanish and English versions, but she was not using the English one.

In regards to the difficulties in understanding a different culture, one situation appeared when using an application game about the UK political system by participant Pb10, she could not understand the meaning of several words and when she was trying to play the game, she was asking about everything. She is more fluent in English than in Arabic, but she still could not understand the system. She also said that her mother does not know English well enough to help her understand the difficult words.

Another aspect is the conservatism of presenting personal photos of female online, which appeared not to be an issue for the female participant Pb10, as she was posting videos of herself on YouTube and talking about her life. In addition, the caregiver of Pb8 suggested taking a picture of her daughter if it was needed. On the other hand, P1 was more conservative and he does not post any photos of himself online. However, more cultural exploration and mapping the collected data from the interviews to the factors identified in FAASCIT [39] will be discussed in a future paper to examine these cultural factors in more detail.

5 Discussion

From the interviewed participants, it has been shown that the use of social networks differs from one participant to the other, and generalization of experiences would be difficult to make. Each participant has his/her own way of using social networks, and also they all had different educational opportunities, and experienced different situations in their lives. While such variability may be expected, and typical, these insights into individual lives, and uses of technologies, by adult Arabs with ASD are very rare in the literature and thus contribute new knowledge about this largely invisible group in Saudi Arabia.

As mentioned earlier, building independence for adults with ASD is important. However, the participants in our study still required support, P2, Pb13 had difficulties connecting to the Internet and accessing their online accounts, P3 and Pb10 keep their account details saved, but they also needed assistance when they forgot their account log in details. Pb5 needs to get permission from his mother for creating an account online. In addition, some caregivers watch the online activities and use of social media by the

participants, such as the mother of P2 which checks what YouTube videos her son watches, and also makes control of the people her son can chat with on WhatsApp. However, P2 had a Facebook account created by the help of one of his siblings, which his mother did not know about before the interview. This could be argued that the mother is trying to protect her son, and making sure he is in a safe space to prevent him from any vulnerability, but not over controlling him. Additionally, P1 does not has his own device, sharing his sister's device or using his teacher's device might always restrict his independency and also restricts him from using social networks.

P4 and Pb10 were the most active users on social networks. P4 uses Snapchat for posting comedy videos, and uses Instagram to post photos of himself and his drawings. Pb10 uses Tumblr to post her comics, and YouTube for uploading videos of herself talking about her life. They both have a target, which could be a reason for why they are more interested in the use of social networks. In this study, Pb10 usage of social media showed that gender differences was not a factor for her in relation to her use of social media, though this is an aspect that requires further investigation with more participants.

Pb10 was asked about her time spent on the Internet, she replied: "daily, I don't have anything else better to do". However, Pb10 do not have online connections with her friends, she feels lonely but also does not like using Facebook or chatting with people online, because she is not comfortable with her spelling. Pb10's case does not support the claim that adults and adolescents could be more comfortable with online communications as they have less pressure than face-to-face communication [8]. However, Pb5 uses WhatsApp to stay in touch with his old friends, teachers and family members, so the quality of friendship is enhanced by his use of social media. Building friendships and communicating with new people could also be possible as P4 has around 1380 followers on Instagram and is following 2301 other accounts.

The mother of P2 was the one who is more conservative about proving his full name on the written forms and online, and only wrote his first and middle names. This was more of a result of being conservative about the family name and reputation. However, all of the caregivers of the interviewed participants were relaxed and talked openly regarding the diagnosis of autism. Though, the caregiver of Pb11 said that sometimes people in public do not respect a person with a disability, and that she had some bad experiences with people offending her son, which made her decide to isolate herself and her son from many people.

In addition, having proper support from the family, and better educational experiences could have an impact on their social skills and digital literacy and correspondingly in their abilities of using social media. For example, P4, Pb10 and Pb13 are all attending mainstream schools, however, Pb13 is not receiving proper education as claimed by his caregivers, instead of integrating him with the typical developing students who are at the same age and level, they isolated all students with different special needs in one class. The caregivers were not happy with the quality of education provided, as their son is not learning from school. This resulted in his limited language abilities, but there are not many options in their city.

However, some limitations of this study is that the findings were according to what has appeared during the interviews, or what have been told by the participants or their caregivers. There could be more situations facing the participants, which will require

more time spent with the participants and more family support, to be investigated. In addition, the findings were regarding the participants who could be reached and who their family agreed to participate.

6 Conclusion

Previous studies showed that the majority of social skills technologies for people with ASD have been developed for children and mainly in Western countries, and limited research is implemented regarding ASD in Arab countries. From detailed interviews and observations with six high-functioning participants with ASD, this research has documented much individual variability in skills, awareness and autonomy with regard to social media use. Results showed that different high-functioning participants use social networks for different reasons, such as chatting, posting videos and photographs or for educational reasons. For some participants, the use of social media showed the ability to enhance friendship relations and communication with people. However, there was some evidence that conservatism in using social networks by the participants was related to the caregiver's beliefs and restrictions, highlighting the relative interdependency between individual use and wider family context. How such rules and beliefs operate within families, and influence social media use, remains an important and interesting focus for future study.

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