Social Media Usage in Supporting Children with Cognitive Disabilities and Their Caregivers from Saudi Arabia: A Qualitative Analysis

Reem N. Alshenaifi and Jinjuan Heidi Feng
Department of Computer & Information Sciences
Towson University, Towson, MD, USA
ralshe1@students.towson.edu, jfeng@towson.edu
REEM NASSER AIS< Helena
IT doctoral student at Towson University
VA, USA | rahel@students.towson.edu | rahel@mailmu.edu.sa

Work experience

Sacred Heart University, Fairfield, CT, USA
Classroom Learning Assistant
- Meet weekly with the course instructor to discuss student difficulties.
- Work directly with students and provide support as needed.
- Reinforce lessons by reviewing class materials with students.

Majmaah University
Teaching Assistant
- Utilized various teaching methods to teach undergraduate students.
- Prepared course materials by following syllabus guidelines.
- Taught multiple courses including:

Majmaah University, Majmaah, Saudi Arabia
Collaborative Lecturer
- Prepared lesson materials, bulletin board displays, exhibits, equipment, and demonstrations.
- Presented subject matter to students under the direction and guidance of professors, using lectures, discussions or supervised methods.

Education

Towson University
DSc in Information Technology
CPI: 4.0

Sacred Heart University, Fairfield, CT, USA
GRADUATE CERTIFICATES
- Web Development
- Interactive Media
- ASP.Net Technology

Sacred Heart University, Fairfield, CT, USA
Master of Science in Computer Science and Information Technology
Completed credits: 35; CPI: 4.0

Majmaah University, Majmaah, Saudi Arabia
Bachelor’s Degree in Computer
3.87 CPI with First Class Honor
BACKGROUND
Caregivers across the world face challenges when raising a child with a disability.
Many studies have confirmed the substantial value of social support and community belonging for individuals with disabilities and their caregivers

- A positive correlation was observed between the tendency to cope with difficulties and the perceived social support (Mina Popliger, Jessica R Toste, and Nancy L Heath, 2009)

- Parents of children with special needs overcome challenges and learn about their child’s condition best through parent-to-parent communication; this communication is done through online avenues, such as social media (Beth A. DeHoff, Lisa K. Staten, Rylin Christine Rodgers, and Scott C. Denne, 2016)

- Facebook and Yahoo groups successfully assisted caregivers in acquiring information and obtaining social support (Tawfiq Ammari, Meredith Ringel Morris, and Sarita Yardi Schoenebeck. 2014)
Motives

Existing literature related to social media use by people with disabilities and their caregivers mainly focuses on Western users.

Saudi caregivers face unique challenges that might not exist in the Western context.
Investigating how social media is used to support and empower Saudi caregivers of children with cognitive disabilities

- Motivations and concerns
- Role of social media during the COVID-19 pandemic
METHODS
INTERVIEW QUESTIONS

Demographics and Background

General Use of Social Media

Social Media Use Related to Children with Cognitive Disabilities

Government Support

Role of Social Media During COVID-19
PARTICIPANTS

12 female
1 male
5 specialists
6 parents
2 siblings

AGE
19 - 44

8 undergraduate
4 graduate
1 high school

Autism
ADHD
Down syndrome
severe cognitive disabilities
dyslexia
Cerebral Palsy
learning disabilities
brain atrophy
INTERVIEWS PROCEDURES

Online interviews

40 -120 m

2 in English
11 in Arabic
INTERVIEWS ANALYSIS

Thematic analysis (Braun and Clarke, 2006)

- Transcription Translating
- Open Coding in NVivo12
- Themes and Subthemes
- Resolving Disagreement
- Finalizing Themes and Subthemes
FINDINGS
The Use of Social Media by Saudi Caregivers

Motivations
- Information Seeking and Sharing
- Raising Social Awareness
- Community Building
- Communication
- Privacy Concerns
- Negative Discussion
- Misinformation
- Lack of Resources
- Design of Technology

Difficulties and Challenges

Social Media Use During COVID-19
- Downsides
- Usefulness

Opportunities for Enhancements
- Centralized Storage Unit
- Credential Checking
Motivations

- Information Seeking and Sharing
- Raising social awareness
- Expanding communication
- Building communities
Motivations

“Once I knew about my son’s condition, I opened the YouTube immediately to get information about his disability, how to look after him, and how to enhance his case.” (P4)
P3 shared her experience in sharing a hashtag which was directed to the government: “The Ministry of Labor changed the criteria of beneficiaries of the daycare services so that more than half of the children were excluded from the service. Families and specialists released a hashtag #ابقاء_إشعاع_قبول_ذوي_الااعاقة #TurnningOff_admission_ChildrenWithDisabilities] calling for returning to the old criteria. We tweeted and retweeted until the decision was made by king Salman, to restore the old regulations.” (P3)
“I don’t share anything in public [...] but I give advice privately to anyone whom I know have children with the same condition.” (P11)

“I do not share any information outside the scope of my colleagues’ WhatsApp group, and I send [information] to each mother separately.” (P1)
Motivations

Building communities

Part of Online Groups:
- All Specialists
- Three Family Members

“I was confused and shocked... I started to look for people who have a child with the same condition as my son’s.” (P4)
The Use of Social Media by Saudi Caregivers

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Difficulties and Challenges

Privacy Concern

“To be honest, my family prefer not to talk about my sister's condition in front of anyone.” (P7)

Fear of Public Judgment and Negative Comments

“My son is Autistic. I will get attacked, people will tell me that I did not hug him enough and even I am spoiling him too much [...] it used to put me in tears.” (P10)
Difficulties and Challenges

Misinformation
Fake medication & generalized treatment fake news & fake accounts

P1 wondered “[how can someone] identify themselves in their bio as specialists of autism, learning difficulties, delayed speech, etc. This is incorrect! No one can be a specialist in all tracks.”

Lack of Resources
Arabic information and online communities

“Simply because no one had created one and invited me to join.” (P11)

Design of the Technology
Advertisements & abbreviation

“The abbreviation of the information is done in an aggressive way where it becomes too short, misleading, and unclear.” (P9)
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Difficulties and Challenges

Social Media Use During COVID-19

- Usefulness

Opportunities for Enhancements

- Centralized Storage Unit
- Credential Checking

Downsides
Opportunities for Enhancements

Centralized Storage Unit

“I hope there is a place to keep all the files scattered here and there in one center and classify them according to the conditions, functional goals, etc.; as a file bank which has a search engine.” (P1)

Credential Checking

“check credentials of people who claim they are who they are.” (P10)
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  - Downsides
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Social Media Use During COVID-19

**Downsides**

Direct communication with the children and dissemination of misinformation

“I cannot evaluate children correctly; the training of children is not done fully and adequately by the mother due to limitations of understanding.” (P9)

**Benefits**

Spreading virus awareness, facilitating distance learning, and seeking social support

“The center my daughter attends did not provide any online courses but was completely shut down. My daughter’s teacher […] motivates my daughter to continue learning. She sent me a package of activities via WhatsApp to implement them with my daughter.” (P8)
DISCUSSION AND CONCLUSION
Caregivers increased their use of social media regarding their child’s condition after the initial diagnosis.

Parents are hesitant to ask private questions regarding their child’s condition due to fear of public judgment and social stigma.

Consistent with parents from the US (Tawfiq Ammari and Sarita Schoenebeck, 2015)

This finding is consistent with an early study in which blind users felt hesitant to use their social networks as a Q&A avenue to their vision-related (Erin L. Brady, Yu Zhong, Meredith Ringel Morris, and Jeffrey P. Bigham, 2013)
Studies conducted in Western context confirmed the significant value of online communities in supporting their members (Beth A. DeHoff, Lisa K. Staten, Rylin Christine Rodgers, and Scott C. Denne, 2016) & (Tawfiq Ammari, Meredith Ringel Morris, and Sarita Yardi Schoenebeck, 2014)

Three out of eight family members in our study belonged to online groups. This may indicate low engagement in online communities among Saudi parents and family members of children with cognitive disabilities.

Their limited engagement may be due to the scarcity of Arabic resources, dedicated online communities and/or privacy concerns.
RECOMMENDATIONS

To address the lack of Arabic resources:

(1) Drawing guidelines and allocating funding by the government to develop social media content in Arabic

To encourage network socialization

(1) Incorporating online communities as a part of educational centers’ technological plans

(2) Initiating special interest communities by social activists

(3) Legislating data privacy policy to protect the rights of caregivers and their children on social media
REFERENCES


