

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

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Presenter Resume

REEM NASSER ALSHENAIFI

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Work experience

Sacred Heart University, Fairfield, CT, USA

Aug 2017 - May 2018

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

2012 - Present

Teaching Assistant

- Utilized various teaching methods to teach undergraduate students.
- Prepared course materials by following syllabus guidelines.
- Taught multiple courses including;

Software Engineering & Electronic Business Systems, Web Engineering and Its Applications, Computer Programming Using C++, Programming of Databases, Selected Topic in Computer (Web Development), Introduction to Computer and Its Applications and Educational Techniques & Communications Skills.

Majmaah University, Majmaah , Saudi Arabia

2010 - 2012

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

Aug 2018 - Current

D.Sc in Information Technology

GPA: 4.0

Sacred Heart University , Fairfield, CT, USA

Aug 2016 - May 2018

GRADUATE CERTIFICATES

- Web Development
- Interactive Media
- ASP.Net Technology

Sacred Heart University , Fairfield, CT, USA

Aug 2016 - May 2018

Master of Science in Computer Science and Information Technology

Completed credits: 39 ; GPA: 4.0

Majmaah University , Majmaah , Saudi Arabia

Sep 2006 - Jul 2010

Bachelor's Degree in Computer

3.87 GPA with First Class Honor

BACKGROUND

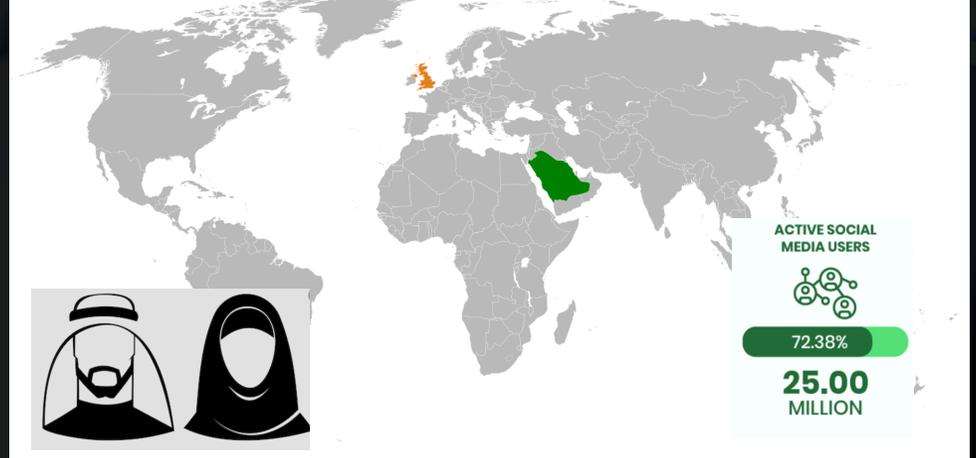
Caregivers across the world face challenges when raising a child with a disability.



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.

RESEARCH AIM

- ❖ 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

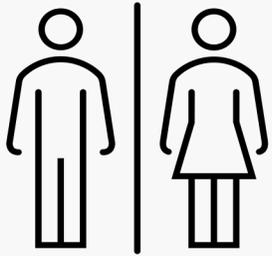
Social Media Use Related to Children with Cognitive Disabilities

Government Support

Role of Social Media During COVID-19



PARTICIPANTS



12 female
1 male



5 specialists
6 parents
2 siblings



19 - 44

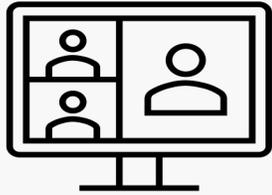


8 undergraduate
4 graduate
1 high school

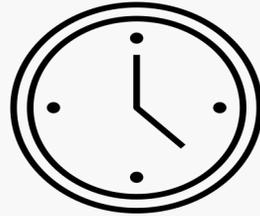


Autism
ADHD
Down syndrome
severe cognitive
disabilities
dyslexia
Cerebral Palsy
learning disabilities
brain atrophy

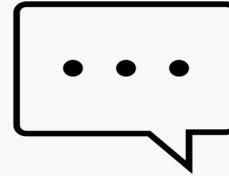
INTERVIEWS PROCEDURES



Online
interviews



40 -120 m



2 in English
11 in Arabic

INTERVIEWS ANALYSIS

Thematic analysis (Braun and Clarke, 2006)

Transcription
Translating

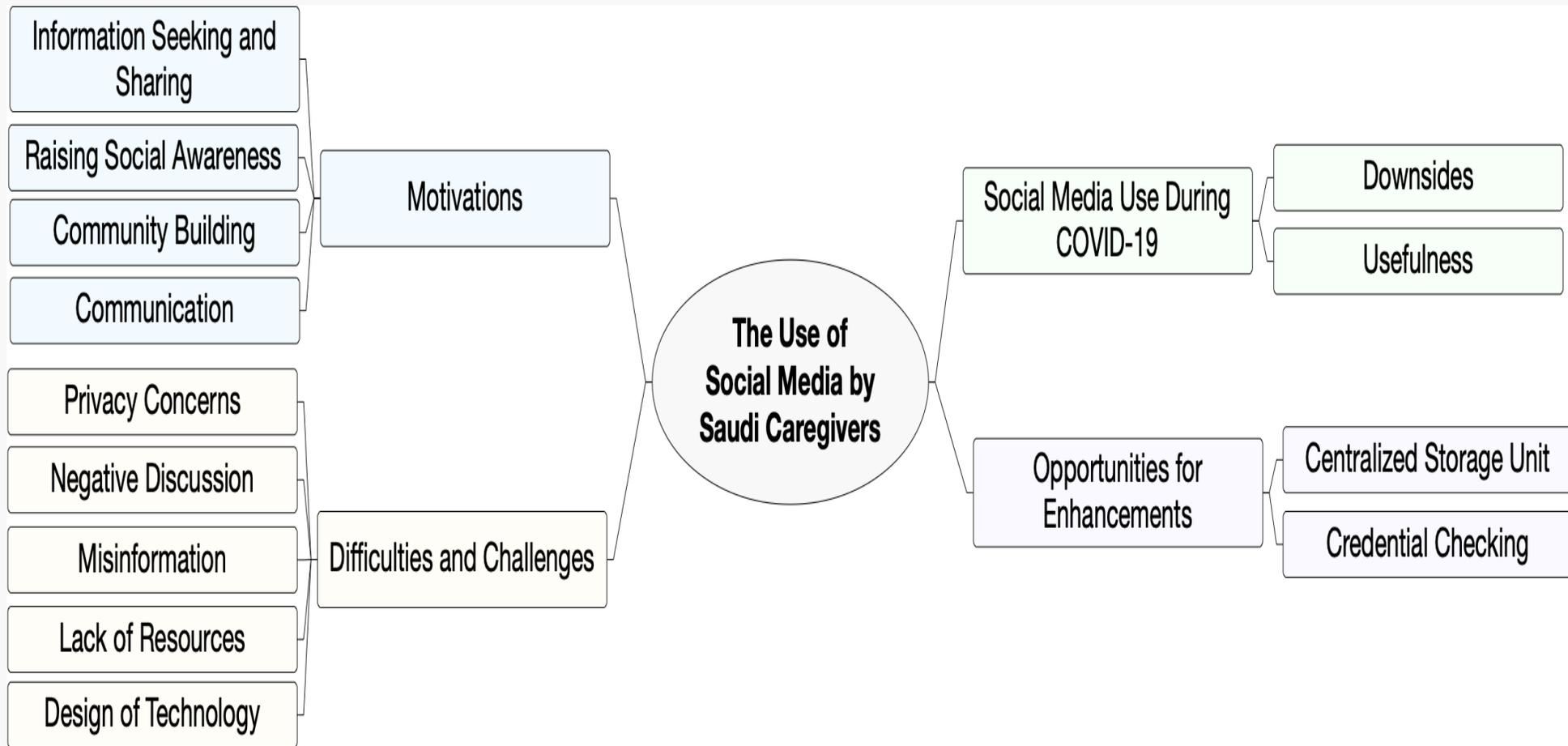
Open Coding
in NVivo12

Themes and
Subthemes

Resolving
Disagreement

Finalizing
Themes and
Subthemes

FINDINGS





Information Seeking and Sharing



Raising social awareness



Expanding communication



Building communities

Motivations

Motivations



Information Seeking and Sharing

“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)

Motivations



Raising social awareness

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 #اييقاف_اشعار_قبول_نوي_الاعاقه [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)

Motivations



Expanding communication



Informational Support

“I don’t share anything in public [...] but I give advice privately to anyone whom I know have children with the same condition.” (P11)



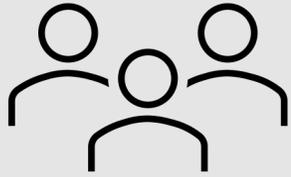
private Groups
Private one to one communication

“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

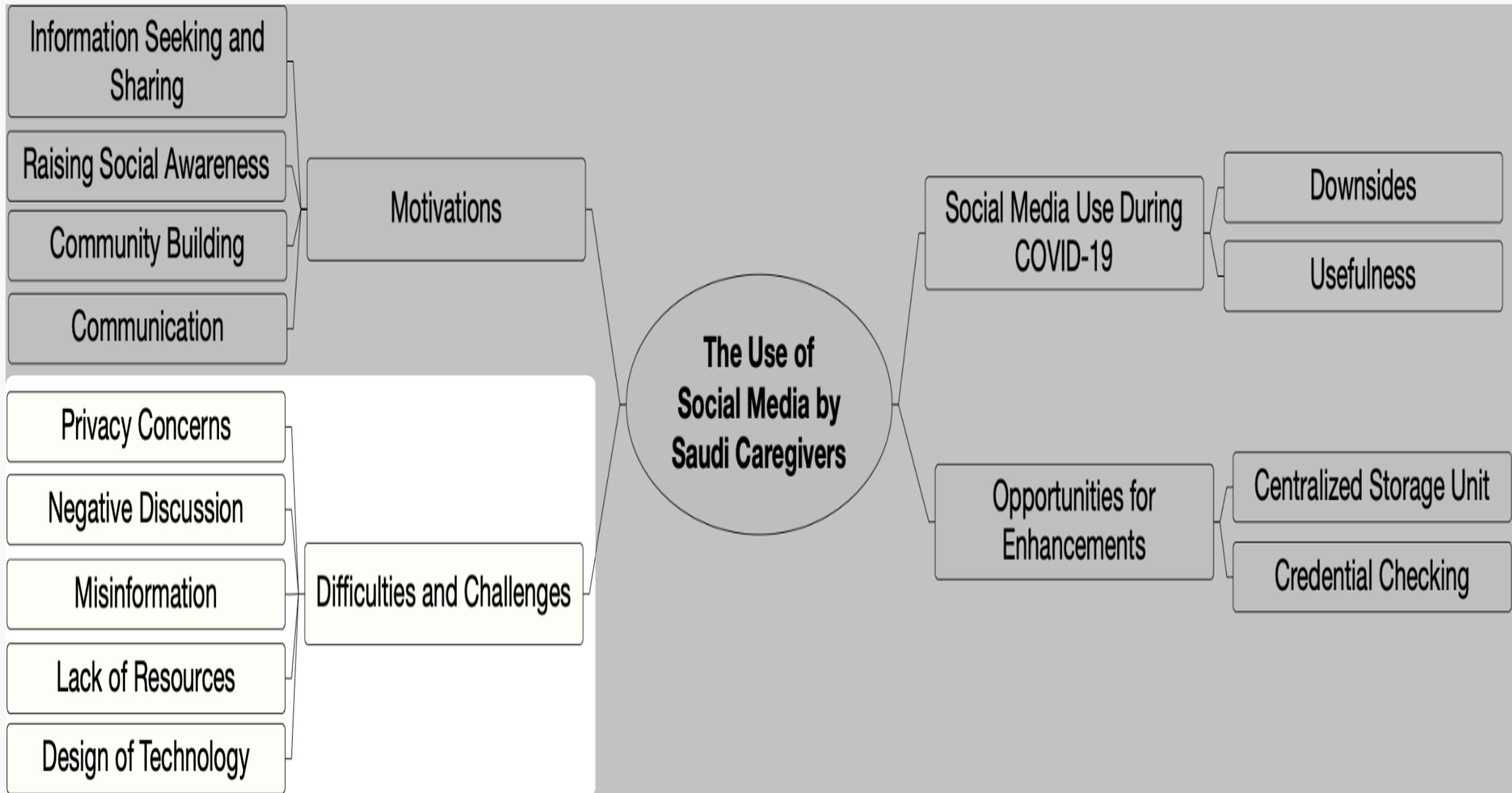


Part of Online Groups:

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)



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

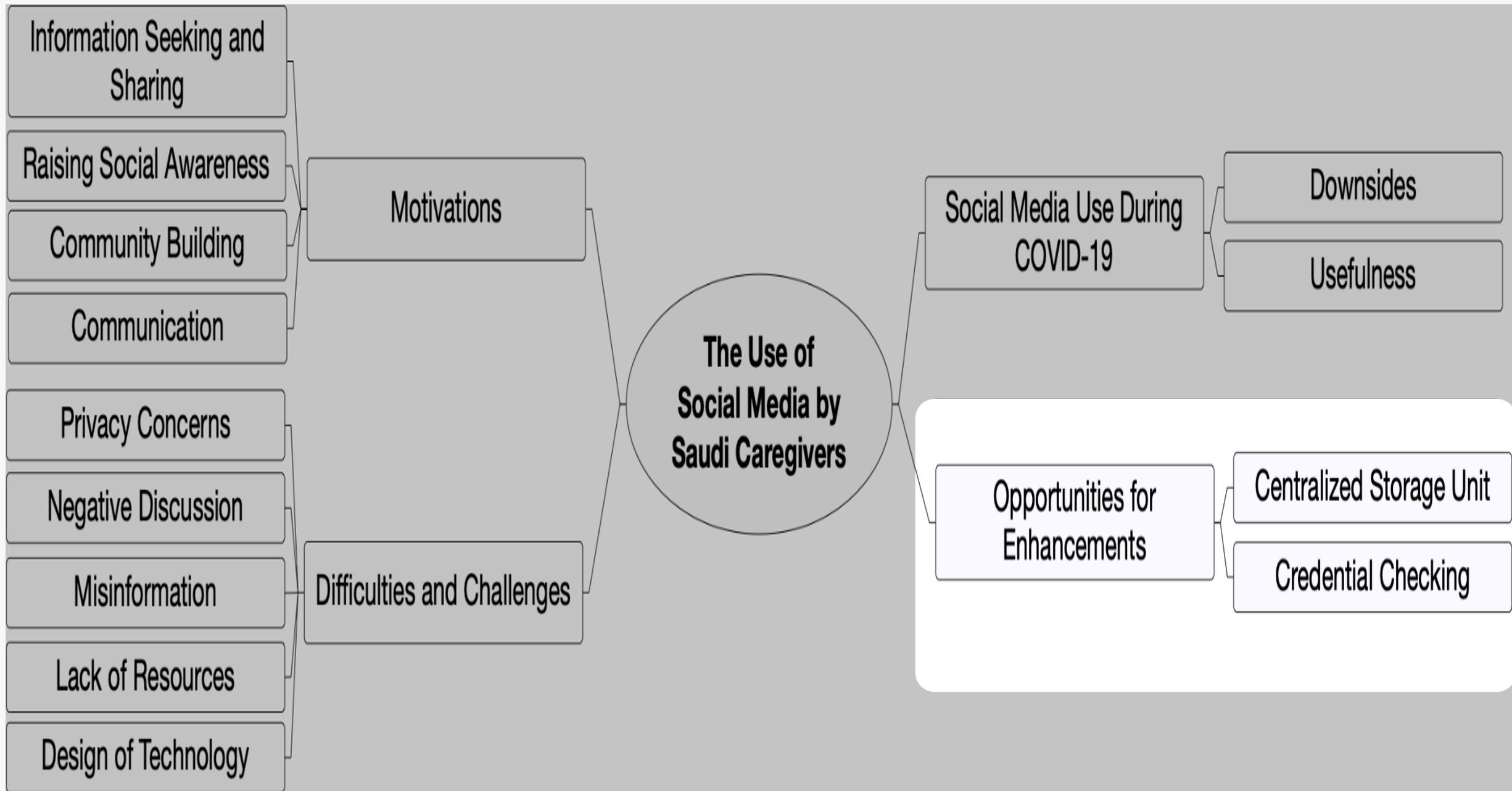
“Simply because no one had created one and invited me to join.” (P11)



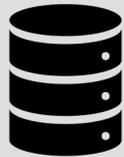
Design of the Technology

Advertisements & abbreviation

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



Opportunities for Enhancements



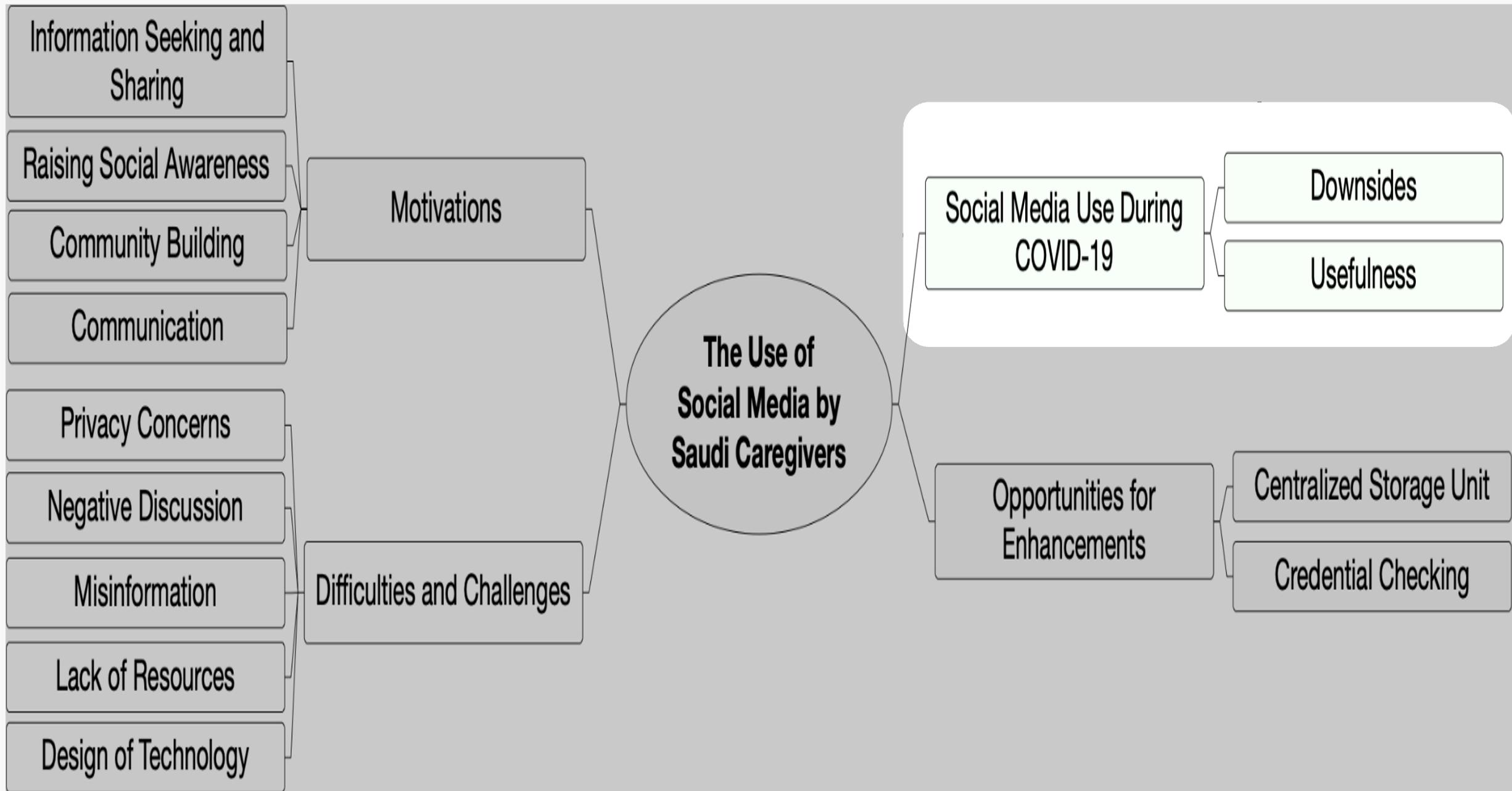
Centralized Storage Unit

"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)



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

SOCIAL MEDIA HAS THE POTENTIALS TO EMPOWER SAUDI CAREGIVERS AND MEET THEIR NEEDS

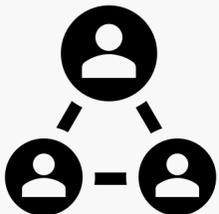
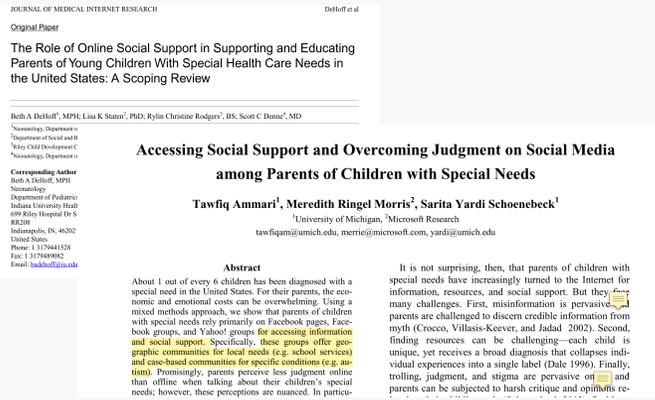
Caregivers increased their use of social media regarding their child's condition after the initial diagnosis.

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

1. M. Popliger, J. R. Toste, and N. L. Heath, "Perceived social support and domain-specific adjustment of children with emotional and behavioural difficulties," *Emotional and behavioural difficulties*, vol. 14, no. 3, pp. 195–213, 2009.
2. B. A. DeHoff, L. K. Staten, R. C. Rodgers, and S. C. Denne, "The role of online social support in supporting and educating parents of young children with special health care needs in the United States: a scoping review," *Journal of medical Internet research*, vol. 18, no. 12, p. e333, 2016.
3. T. Ammari, M. R. Morris, and S. Y. Schoenebeck, "Accessing social support and overcoming judgment on social media among parents of children with special needs," in *Proceedings of the 8th International Conference on Weblogs and Social Media, ICWSM 2014*, 2014, pp. 22–31.
4. T. Ammari and S. Schoenebeck, "Networked Empowerment on Facebook Groups for Parents of Children with Special Needs," in *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems*, 2015, pp. 2805–2814, doi: 10.1145/2702123.2702324.
5. E. L. Brady, Y. Zhong, M. R. Morris, and J. P. Bigham, "Investigating the appropriateness of social network question asking as a resource for blind users," in *Proceedings of the 2013 conference on Computer supported cooperative work - CSCW '13*, 2013, p. 1225, doi: 10.1145/2441776.2441915.