

Mothers' use of social media as a health information source about child autism in Saudi Arabia

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ABSTRACT

In Saudi Arabia, mothers of autistic children face difficulties accessing accurate information and reliable support due to limited services and social stigma. This paper presents early findings from an ongoing qualitative study exploring mothers' information behaviour, including how they seek, evaluate, and use autism-related information via social media and AI tools. Based on interviews with six mothers of autistic children, the study shows how social media provides emotional validation, peer support, and practical insights. Mothers evaluate information based on how often they encounter it, personal experience, and ChatGPT, which they use to verify, simplify, or explain information. Alexa also became a communication aid for a blind autistic child. These findings reveal how mothers actively manage uncertainty and compensate for gaps in professional support. The paper contributes to understanding autism-related information behaviour in a Saudi context. It highlights the need for more accessible, accurate digital resources for underserved families lacking trained professionals, public awareness, and inclusive education options.

KEYWORDS

Autism Spectrum; Neurodiversity; Information Behavior; Social Media; Generative AI.

INTRODUCTION

In the Kingdom Saudi Arabia (KSA), especially in poorer regions, families of autistic children face many challenges, including difficulties accessing accurate information, support services, and timely diagnosis (Khan et al., 2020). Delays in diagnosis are often linked to low socio-economic status, limited parental education, and lack of awareness (Malwane et al., 2022). Research has shown that many parents in KSA lack knowledge about autism, which leads to misconceptions, stigma, and further isolation of autistic children and their families (Alharbi et al., 2019; Khalil et al., 2020). There is a stigma in KSA, and a lack of access to formal information, and makes it more difficult for families to seek help (Bakombo et al., 2023). Many parents of autistic children in KSA continue to report that the lack of autism awareness remains a serious challenge (Almasoud & Ain, 2023).

Families with autistic children from low-income areas in Saudi Arabia often face barriers to accessing autism-related services due to limited resources, untrained school staff, and exclusionary attitudes (Al Awaji et al., 2024; Khan et al., 2020; Otaif et al., 2023). As a result, many parents turn to social media for information and support, despite concerns about accuracy (Skafle et al., 2024). Recent findings also show that tools like ChatGPT are emerging as helpful resources for answering parents' questions (McFayden et al., 2024).

This paper presents early findings from an ongoing study on how parents and teachers in Saudi Arabia seek, evaluate, and use autism-related information through social media. Focusing on interviews with six mothers, the study highlights how they access information and support in a context shaped by limited services and stigma. These emerging insights offer implications for future research, policy, and practice. The next section reviews the literature informing this study.

LITERATURE REVIEW

Information Behaviour and Autism

Autism is understood through different models: the medical model views it as a clinical condition within the individual (Oliver, 1990; Shakespeare, 2006), while the social model focuses on societal barriers. The neurodiversity perspective sees autism as a natural variation in human functioning (Bertilsdotter Rosqvist et al., 2020). Language use is also debated—many professionals use person-first terms, but many autistic individuals prefer identity-first language (Kenny et al., 2016), which this study adopts.

Parents often struggle to access clear information before diagnosis and turn to online sources and other parents for support, as many resources are aimed at professionals (Laurin & Andersson, 2024; Weissheimer et al., 2020; Chávez & Sabelli, 2020; Gibson & Hanson-Baldauf, 2019). They prefer concise, relatable information and find peer

experiences more helpful than professional advice, which may be constrained by systemic limitations (An et al., 2019). Online communities offer emotional support and reduce isolation, especially for mothers facing stress, stigma, and guilt (Dauman et al., 2019; Laurin, 2023).

Use of Social Media for Health Information

Social media platforms like Facebook, YouTube, TikTok, WhatsApp, and Twitter are widely used by families of autistic individuals to access information and support, especially in KSA, where they help fill service gaps (Abel et al., 2019; Bellon-Harn et al., 2020; Zenone et al., 2021; Abualhommos et al., 2022; Alnemary, 2017; El Kheir et al., 2021). While social media can raise awareness and reduce stigma, it can also spread misinformation and reinforce narrow views (Aragon-Guevara et al., 2023). Platforms like TikTok influence user perception through repeated content, a process known as algorithmically mediated biographical illumination (Cheney-Lippold, 2011; DeVito, 2022; Lee et al., 2022), which may support self-discovery but also risk inaccurate conclusions (Alper et al., 2025). Parents often form online communities to exchange emotional and informational support (Bryan et al., 2020; Frey et al., 2022), but low health literacy, limited expert input, and difficulty verifying content can lead to confusion and anxiety (Drouin et al., 2020; Price et al., 2018; Muhammed & Mathew, 2022; Shu et al., 2020). The persistence of myths, such as the vaccine-autism link, highlights the need for improved digital and health literacy (Skafle et al., 2022). Frey et al. (2022) also found that parents' understanding was shaped by translation tools, healthcare consultation, intuition, and visually engaging content.

Artificial Intelligence (AI) in the Autism Context

Generative AI is being explored as a tool to support autistic individuals through personalised learning experiences (Johnson et al., 2023). Intelligent Personal Assistants like Alexa, Siri, and Google Home have shown potential in improving communication and social interaction for autistic users, including use cases such as reducing public speaking anxiety (Ali et al., 2020; Burke et al., 2018; Cha et al., 2021; Milne et al., 2010; Wang et al., 2020).

Integrating AI with visual and interactive robotics presents a promising approach to supporting autistic individuals in assessment, intervention, and neurodevelopment (Bertacchini et al., 2023). AI-driven analytics can also help caregivers and educators identify behavioural patterns and tailor support more effectively (Xing, 2024).

Although research on parents' use of generative AI for autism-related information is still emerging, Xing (2024) found that AI-based training tools can help parents apply learning strategies at home, especially in low-resource settings. However, concerns remain about data privacy and how such tools handle children's personal information (Hume et al., 2021).

RESEARCH QUESTIONS

To explore these issues in depth, the study uses semi-structured interviews with mothers of children diagnosed or suspected to have autism, and seeks to answer the following research questions:

1. How do mothers from KSA use and evaluate autism-related information from social media and other sources to inform their understanding and decision?
2. How does information from social media compare with more traditional or formal sources of autism-related information?
3. What types and formats of information do mothers prefer when seeking autism-related content?

RESEARCH METHODOLOGY

To answer the research questions, this study used a qualitative approach based on semi-structured interviews, with analysis conducted using Braun and Clarke's (2022) thematic analysis. This approach allowed for an in-depth exploration of how mothers of autistic children in Saudi Arabia seek, evaluate, and use autism-related information.

An interview guide was used to focus the discussions on key topics, including: 1) The current availability of autism-related services in Saudi Arabia. 2) Parents' needs to support the integration of autistic children in schools.

3) The availability of autism-related information on social media and other sources. 3) How parents use these sources to find information. 4) How they evaluate the accuracy and usefulness of the information they find.

The themes discussed in the findings section were developed based on mothers' responses to the topics outlined in the interview guide, including their use of social media, information needs, evaluation strategies, and experiences with autism-related services.

After receiving ethical approval from the University of Sheffield and permission from the Ministry of Education to conduct interviews in schools, six mothers were recruited through snowball sampling. Initial contact was made through a primary school with autism classrooms, and additional participants were reached via online communities. The children were aged between 6 and 10 years; some had formal autism diagnoses, while others were suspected of

having autism based on family observations, self-awareness from the mothers, or school referrals. In Saudi Arabia, schools are permitted to report unusual student behaviour and notify families, which in some cases prompted the mothers to seek further evaluation.

Interviews were conducted in Arabic and arranged based on the mothers' preferences. One was conducted in person, while five were held online via Google Meet. All interviews were audio recorded with informed consent and transcribed for analysis. Although fathers were invited, only mothers participated, reflecting common caregiving roles in the local culture. The study followed ethical procedures, including participant anonymity and secure data storage.

FINDINGS

The analysis identified four key themes: 1) using social media for emotional and informational support, 2) evaluating information through personal experience, emotion, Evaluation through Experience, Feelings, Finding information repeated, and AI guidance, and AI tools, 3) using AI like ChatGPT and Alexa for both support and communication, and 4) the influence of algorithms on how mothers access and act on information. These themes show how mothers navigate uncertainty and digital environments to meet their children's needs.

Information Seeking in Social Media

In this study, mothers predominantly use social media platforms like TikTok, and YouTube to learn about autism. These platforms were easy to access and valued for their relatability, simplicity, and emotional connection, especially compared to official sources, P3 said *"TikTok is better than any other social media platform. You find everything and you don't need to spend money on initial diagnosis"*. Also, P2 said, *"I follow mothers of autistic children... makes me feel like I'm not alone."* The Ministries of Health website, was often dismissed as too general or unhelpful, P2 said, *"The Ministry of Health? No. They just provide generic info."*

For another mother, social media was chosen because they can information-seeking in secret. One preferred YouTube, where she could find stories from parents like herself while still in denial, P1 said *"I kept searching secretly. on YouTube, I found people like me."*

Another mother spent nearly a year seeking information about autism before feeling ready to pursue a formal diagnosis, P4 said *"After seeking information on YouTube, I told the doctor, 'I'm ready now. I know everything about autism. I'm ready to get my son diagnosed. I know he has autism, but I want to make it official so I can request government support.'" This example shows how social media supports not just information-seeking, but also emotional readiness, self-reflection, and gradual acceptance, especially for mothers facing diagnosis alone or in challenging conditions.*

Evaluation through Experience, Feelings, Finding information repeated, and AI guidance

Mothers evaluated autism-related information based on what was practical, felt relevant, and emotionally convincing. Without trusted professional guidance, one relied on experiential justification to decide whether to accept or reject information, P6 said *"I evaluate information by trying it."* Another mother evaluated information based on emotional judgement, P2 said *"I knew in my gut it was a scam."*

One mother said she starts to believe the information only when she sees it repeatedly across platforms, which gives it more weight and credibility in her eyes, P1 said *"When I see the same information many times, I start to feel it's true."*

Another mother described using ChatGPT to verify what she reads or not understand, often asking it to explain things in a simple way and even requesting sources to confirm the accuracy of claims, P3 said *"I ask ChatGPT if something is true, and ask ChatGPT to explain to me as if I were a kid, and I tell it to give me the source."*

These quotations show how mothers construct their own methods of evaluating online information they found, repetition, emotional convincing, AI verification, and personal observation, especially when formal resources are not accessible or trusted.

Artificial Intelligence as Communication and Support

When professional systems were inaccessible or exclusionary, mothers found alternative sources of support in AI-powered consumer tools like Alexa and ChatGPT. One mother, whose blind and nonverbal autistic son had been rejected from schools and therapy centers, described how using Alexa became a turning point in her son's

communication development. P6 said *“They told me, ‘Your son is blind we can’t help him because autism therapy depends on eye contact.’ That’s when I gave up searching. He would ask Alexa to tell him a story or ask what time it is... that helped him communicate more.” They shut the doors in my face—schools and doctors—because my son is blind. But Alexa helped my son to talk. Now, I rely on Alexa. It’s the only thing that worked.”*

Similarly, another mother used ChatGPT not just for information but also as an emotional companion that provided clear, reliable, and timely guidance, P3 said *“ChatGPT calms me when I’m upset. Even when I was angry, ChatGPT said do you need anything I am here to help you, my husband doesn’t do that” “I trust ChatGPT. It simplifies what I need and shows me how to proceed.”* These tools acted as nonjudgmental, accessible, and emotionally attuned supports, stepping in where human systems failed to offer culturally and linguistically relevant care.

Algorithmic Influence on Parental Information Behaviour

Algorithms on social media platforms such as TikTok and Instagram were described as affecting the behaviour of mothers’ information behaviour with autism-related content. One mother had stopped seeking information, but TikTok videos brought back her doubts and fears, triggering her to restart her daughter’s diagnosis, P4 said *“I stopped seeking until videos appeared, then I had doubts and scared again and started seeking similar videos, and started diagnosing my daughter again to see if she has autism.”*

Another mother encountered an English-language Instagram video in which a woman confidently claimed vaccines cause autism. The speaker’s appearance, language, and professionalism made the video highly convincing. P1 said, *“I was browsing Instagram when a video suddenly appeared with a woman talking about vaccines. She looked like an important person, very confident, and spoke English... even the comments were in English, so I believed her more. I didn’t give my daughter the vaccine because I think that’s what happened to my son.”*

These experiences show that algorithmic platforms can shape health decisions by re-engaging mothers or reinforcing misinformation, especially when they are emotionally vulnerable.

DISCUSSION

This study explored how mothers in KSA use social media and AI to address their information and emotional needs amid stigma and limited support. Platforms like TikTok and YouTube provided practical guidance and emotional reassurance, often in private and relatable ways—consistent with findings by Bryan et al. (2020) and Chávez & Sabelli (2020). Social media supported emotional readiness, as seen in cases where mothers engaged with content before seeking diagnosis. Mothers evaluated information through repetition, intuition, and personal experience, reflecting patterns noted by Frey et al. (2022). ChatGPT was used for simplification and verification, showing AI’s role in informal, self-directed evaluation (Johnson et al., 2023; Xing, 2024).

While social media can raise autism awareness, algorithm-driven content may also spread misinformation or trigger fear, especially when presented by confident speakers (Aragon-Guevara et al., 2023). Some mothers in this study made important health decisions based on such content, highlighting the need for digital literacy and culturally relevant support. Relatable sources like TikTok and parent stories were preferred over official ones. Tools like ChatGPT and Alexa also provided emotional and communication support, consistent with previous research (Wang et al., 2020; Bertacchini et al., 2023; Xing, 2024).

This study enhances understanding of autism-related information behaviour in underserved areas of KSA by showing how mothers develop personal strategies to support their autistic children using tools like ChatGPT and Alexa. Social media helps meet emotional and informational needs by offering privacy, relatability, and a nonjudgmental environment. These findings support existing research by highlighting how emotional resilience and self-guided learning influence how mothers seek and use autism-related information. The study also suggests practical and research implications: future work could explore how social media and AI can support autism caregiving, especially in low-resource settings. In practice, these tools may help raise awareness and reduce stigma when used to share accurate, culturally relevant content. Improving parents’ digital literacy is essential to help them evaluate online information critically.

CONCLUSION

This study explored how mothers in KSA use social media and other tools, such as AI to find and assess autism-related information. Early findings show they actively seek support through platforms like ChatGPT and Alexa, especially when formal services are lacking. Future research should include fathers and explore long-term impacts.

GENERATIVE AI USE

GPT-4 was used to enhance grammar and clarity. All outputs were carefully reviewed to ensure accuracy and preserve the original meaning. No part of the text was solely generated by the tool. Responsibility for the final content remains with the submission.

AUTHOR ATTRIBUTION

The following roles reflect the specific contributions of each author to this paper.

Bayan Alasmari: Conceptualisation, methodology, data curation, formal analysis, investigation, writing – original draft.

Dr Andrew M. Cox: Supervision, writing, review and editing.

Dr Sophie Rutter: Supervision, writing, review and editing.

Dr Sara Vannini: Supervision.

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