

This is a repository copy of Challenges for people with depression in using online mental health communities (OMHCs) in Saudi Arabia.

White Rose Research Online URL for this paper: <u>https://eprints.whiterose.ac.uk/id/eprint/227110/</u>

Version: Published Version

Proceedings Paper:

Alrashed, S., Bath, P.A. orcid.org/0000-0002-6310-7396 and Koya, K. (2025) Challenges for people with depression in using online mental health communities (OMHCs) in Saudi Arabia. In: Andrikopoulou, E., Gallos, P., Arvanitis, T.N., Austin, R., Benis, A., Cornet, R., Chatzistergos, P., Dejaco, A., Dusseljee-Peute, L., Mohasseb, A., Natsiavas, P., Nakkas, H. and Scott, P., (eds.) Intelligent Health Systems – From Technology to Data and Knowledge: Proceedings of MIE 2025. Medical Informatics Europe 2025: Intelligent health systems – From technology to data and knowledge, 19-21 May 2025, Glasgow, Scotland. Studies in Health Technology and Informatics, 327. IOS Press, pp. 1413-1417. ISBN 9781643685960

https://doi.org/10.3233/SHTI250635

Reuse

This article is distributed under the terms of the Creative Commons Attribution-NonCommercial (CC BY-NC) licence. This licence allows you to remix, tweak, and build upon this work non-commercially, and any new works must also acknowledge the authors and be non-commercial. You don't have to license any derivative works on the same terms. More information and the full terms of the licence here: https://creativecommons.org/licenses/

Takedown

If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing eprints@whiterose.ac.uk including the URL of the record and the reason for the withdrawal request.



Intelligent Health Systems – From Technology to Data and Knowledge E. Andrikopoulou et al. (Eds.) © 2025 The Authors. This article is published online with Open Access by IOS Press and distributed under the terms of the Creative Commons Attribution Non-Commercial License 4.0 (CC BY-NC 4.0). doi:10.3233/SHTI250635

Challenges for People with Depression in Using Online Mental Health Communities (OMHCs) in Saudi Arabia

Sara Alrashed^{a,1}, Peter A. Bath^a, and Kushwanth Koya^a ^aInformation School, University of Sheffield, Sheffield, UK ORCiD ID: Peter A. Bath <u>https://orcid.org/0000-0002-6310-7396</u>; Kushwanth Koya: <u>https://orcid.org/0000-0002-7718-1116</u>

Abstract. Depression is one of the most prevalent mental health illnesses and a significant public health concern in Saudi Arabia. Due to misconceptions about mental health diseases, such as depression, in Saudi Arabia, there is widespread stigma. Many people with depression, therefore, seek health information via social media such as blogs, microblogs, and online communities. Online mental health communities (OMHCs) have been developed only recently in the country. This study explores the challenges people experience when engaging in OMHCs. A sample of 1,422 posts was generated from two OMHCs and analyzed using inductive thematic analysis. Three main themes were identified: misinformation, triggering vulnerability, and judgment. Findings from this study will be shared with the OMHCs and will help administrators to develop strategies and policies to enhance the experience of people with depression in using OMHCs.

Keywords. Online mental health community, depression, Saudi Arabia, challenges.

1. Introduction

Mental health illnesses have pervasive and negative impacts on individuals and society. Depression is one of the most detrimental and complex mental health illnesses [1]: approximately 3.8% of the global population currently suffers from depression [2] and the number of people affected is increasing. Depression affects quality of life in various ways and can lead to increased levels of morbidity and stigma [1]. Stigma related to depression causes individuals to face negative societal attitudes, devaluation, prejudice, discrimination and disempowerment, which can contribute to isolation, self-disparagement, feelings of rejection, and a lack of support and understanding [1].

In Saudi Arabia, depression is a leading mental health problem, with severe depression estimated to affect about 12.7% of the population [3]. The prevalence varies widely across the country's 13 regions, ranging from 8.2% in Qassim and Hail to 19.5% in Najran. Odah et al. [4] reported an average depression prevalence of 68.1% in Southwest Saudi Arabia, with the breakdown being mild (28.2%), moderate (21.9%), moderate to severe (12%), and severe (6%). These high rates of depression are a significant public health concern in Saudi Arabia. The stigma associated with mental health issues is widespread, often deterring many individuals from seeking and accessing

¹ Corresponding Author: Sara Alrashed; E-mail: saalrashed1@sheffield.ac.uk.

mental health care due to misconceptions about mental health [5]. Many people with depression, therefore, use social media to seek health information. Social media include platforms, such as online communities and groups, where people can meet virtually to share various resources and social support. Online health communities (OHCs) are virtual places where individuals with similar health conditions communicate and share information or other resources. Individuals with a variety of health conditions use OHCs to share personal experiences and access the information needed [6,7]. Online mental health communities (OMHCs) are OHCs where people share information, experiences and emotions: these may be linked to specific mental health conditions, such as depression and are where members of OMHCs often seek social support [8]. Within these OMHCs, which afford privacy, convenience, and a sense of belonging, many people with depression share sensitive topics that they might not be in the physical world [9].

No previous study has investigated the challenges faced by people with depression when using OMHCs in Saudi Arabia. The aim of this study was to undertake an inductive analysis of posts in Saudi OMHCs to explore challenges for people with depression.

2. Methods and Results

This study used a qualitative approach to explore the challenges associated with people with depression in Saudi OMHCs. Using online posts enables the challenges that people experience to be investigated without involving users directly [6,7,9]. Two OMHCs aimed at patients with depression (mild to severe) were selected, and consent to use these was obtained from the gatekeepers. Each OMHC had a different structure. Amer OMHC (name altered for privacy reasons) is a platform approved by the Saudi Health Ministry and has various forum boards moderated by psychologists. It was selected in this study as the largest OMHC platform in Saudi Arabia. Four boards were purposively sampled: health, general, self-development and recovery stories. The second OMHC, the Telegram public group (TG), which was selected as one of the first Saudi OMHCs, discusses various aspects of depression and is also moderated. Ethics approval was granted by the University of Sheffield (May 2024; Application 059127).

The data sample consisted of 229 threads (1,422 posts) from the TG and Amer boards, from 393 unique members. Relevant posts were sampled to reflect diverse views and perspectives among users. Posts were anonymized and usernames of posters were replaced with pseudonyms to protect confidentiality and privacy. Quotes used in this study were translated into English post-analysis. For posts containing identifiable markers following translation, the wording was altered while preserving the original meaning [10]. The anonymized posts were analyzed using ATLAS.ti (Qualitative analysis software). Data were analyzed inductively in Arabic using reflexive thematic analysis [11,12]. Data familiarization was undertaken when collecting and anonymizing the posts and reading them multiple times while making notes. Data were coded and stored using ATLAS.ti and discussed in a flexible, iterative process within the research team. In reflexive thematic analysis, data analysis was shaped by the researchers' interpretations, explanations and experiences [12]. Themes were developed by categorizing groups of codes (grouping and regrouping). Three main themes were identified based on online posts from people with depression: misinformation, triggering vulnerabilities, and judgment. Integrating these themes can provide an understanding of the challenges associated with people with depression in Saudi OMHCs.

2.1. Misinformation

Although OMHCs provide individuals experiencing depression with the information needed to help and support them, these sources can contain inaccuracies or misinformation. Although we were not able to quantify it, this was more apparent in TG: this may have been because it was not moderated by therapists, unlike Amer, which is approved and moderated by the Saudi Health Ministry.

The most common misconception observed was that antidepressant medicine can cause addiction, reflecting erroneous beliefs prevalent in Saudi society; however, most antidepressants are not addictive [13]. Abia shared their experience in reply to Marwa, who was diagnosed with major depression and was prescribed antidepressants by a psychiatrist: "*The doctor prescribed me pills to treat depression, but I got addicted to them to the point where I still take them, even though I'm supposed to stop. I can't live without them.*" (Abia, Amer-General). Marwa hesitated to take her medication due to the mistaken belief conveyed in the real world. Although many posters encouraged Marwa to adhere to her treatment by sharing their successful experiences taking medicine, comments such as Abia's could discourage someone from adhering to their treatment.

"But I always believe that the more you're able to solve the issue without medications and chemical compounds... Because, in the end, psychiatric medications are a form of addiction." (Salman, TG). Salman's view represents common Saudi beliefs associated with antidepressant medication addictions [14], and he preferred natural treatments. Despite comments being posted by people who have taken antidepressants, and have accordingly experienced improvements in their lives, sharing misinformation based on personal anecdotes or beliefs, such as those related to addiction, can affect users, especially those with severe depression, and may encourage them to deviate from the interventions prescribed by psychiatrists. It was clear that many people with depression knew the true facts that most antidepressants do not cause addiction; however, in the real world and Saudi society, many people have this misconception, including family members of people with depression. People with depression may be prevented from consulting a psychiatrist in Saudi society because of the stigma associated with depression and with taking antidepressants. This may drive people with depression to hide their condition: "The place here [OMHC] is very comfortable for sharing anything." (Danh, Amer-Recovery stories). Although people with depression benefit from using OMHCs in addressing their information needs and receiving social support, it can also expose them to inaccurate information.

2.2. Triggering Vulnerability

People with depression are vulnerable and emotionally sensitive and may be easily affected by issues. When they engage with members of online communities, their sensitivity may increase, potentially triggering feelings, such as sadness or anger.

Many posts shared painful stories, for example, the causes of depression, such as family issues, abuse, serious illness diagnoses, and the grief of loss. For people with depression, reading those comments might trigger some painful memories that can lead to various negative emotions, including fear, anger, and sadness. "After I failed to achieve my goals, they became pointless. I no longer know how to do my routine. I don't know what to look for or where to go... I'm lost. I have started wasting my time during the day, and the important thing is to simply get through the day because there is no passion or goal." (Sherine, Amer-Self-development) Jana and Rana replied: "I'm in the same

situation [©]." (Jana, Amer-Self-development). "OHHH, the same situation. After I lost my dream and my desire and wasted my opportunities, I didn't know what to do with my life. My life passes like scattered dust ..." (Rana, Amer-Self-development). The messages posted by Sherine, Jana and Rana suggest feelings such as hopelessness and regret. Validating Sherine's feelings affected both Jana and Rana, as well as Sherine (since she was expecting someone to support her) and potentially other people who read the thread. Even though many posters receive posts expressing various types of positive emotions, such as empathy, sympathy, love, gratitude and hope, in some cases, people may respond by validating the emotions that the poster felt, leaving the poster and people who replied and potentially people who read those threads in hopeless and vague situations.

2.3. Judgmental

People with depression in Saudi Arabia were using OMHCs to share and discuss sensitive topics that are often difficult to address or may not be acceptable in the real world. Online communities offer a virtual place where people can openly discuss issues such as family problems or abuse, providing a space for them to express themselves and potentially find some relief. For instance, "Hello everyone, I hope you're all doing well. If anyone is feeling lonely or lost, needs someone to listen without judgment, and just wants to vent and feel like they matter and that there are many others like them, I'm here and ready to listen without judgment. Sharing with people who might understand you can really ease the pressure and help you feel better. Sometimes, we just want to feel heard." (Shahad, Amer-Self-development). Shahad was aware of, and understood, the social norms in Saudi society and expressed her willingness to listen to others without criticizing them. Although OMHCs provide a platform for people to share topics that may be difficult to address in the offline world, OMHCs are still somewhat influenced by Saudi societal norms. Despite efforts by many users to offer helpful advice and information, some may be judgmental, which can negatively impact the recipient and possibly others. This may particularly affect people living with depression, who may be more sensitive and prone to feelings of worthlessness in response to such posts. For example: "There is no such thing as a passion; this is a word used when you're distant from God. Make a schedule, do the things you love, live day by day, and don't worry about tomorrow ... " (Zaynab, Amer-General). Zaynab responded to Adil, who had posted that he was experiencing emotional numbress and a loss of passion. Although Zaynab offered him valuable advice, the way she presented it could appear critical, implying that his lack of passion was due to being distant from religion. This could have negatively impacted Adil, potentially making him feel sensitive, isolated, or unwilling to accept her advice. Many people in Saudi Arabia believe that depression is not a physical illness and that the reason people become depressed is a lack of faith or being distant from religion: this perception can lead to judgmental attitudes.

3. Discussion and Conclusions

This study identified three main challenges that people with depression experience in Saudi OMHCs. First, misinformation was a significant challenge within OMHCs, consistent with previous studies on general health and physical disease [15]. Furthermore, misinformation was more prevalent in TG led by non-therapists, aligning with earlier findings [16]. Expert-led OMHCs may have a lower risk of misinformation

compared to peer-led OMHCs. Second, some individuals with depression may exhibit triggering vulnerability. This implies that when they encounter negative content related to their past experiences, it can evoke memories that lead to negative emotions, such as sadness, hopelessness, and anger. This can foster a vicious cycle in which people with depression are often trapped. The vicious cycle of depression describes a self-sustaining pattern of negative thoughts, emotions, and behaviours that can intensify and prolong the symptoms of depression [1]. The third barrier found in this study was judgmental posts. Although relatively few people had an overtly judgmental tone compared to the real world, most of these posts reflect wrong beliefs about the causes of mental illness in Saudi Arabia, such as a person's lack of faith [5]. This study enhances the knowledge of understanding misinformation in OMHCs as further research is needed in this area [16]. The study yields novel insights relating to misinformation in OMHCs: however, further studies, e.g., interviews with users, could explore the challenges that people with depression encounter when engaging in Saudi OMHCs. The study can, therefore, help raise awareness of potential risks, ultimately aiding their reduction. Findings from this study will be shared with the host organizations to help OMHC administrators to establish strategies and policies for users to adhere to in order to mitigate these challenges.

References

- Durbano F, Irtelli F, Marchesi B, editors. Depression What Is New and What Is Old in Human Existence. 1st ed. IntechOpen; 2024. doi: <u>https://doi.org/10.5772/intechopen.1000384</u>
- World Health Organization. Depressive disorder (depression) [Internet]. 2023 Mar 31 [cited 2024 Oct 16]. Available from: <u>https://www.who.int/news-room/fact-sheets/detail/depression</u>
- [3] Alhabeeb AA, Al-Duraihem RA, Alasmary S, Alkhamaali Z, Althumiri NA, BinDhim NF. National screening for anxiety and depression in Saudi Arabia 2022. Front Public Health. 2023; 11:1–12.
- [4] Odah M, Ewis A, Alkudaysi FM, Alhasani T, Alessi AA, AlKudaysi YMY, et al. Prevalence of depression among the adult population in southwestern Saudi Arabia: a cross-sectional, communitybased study. Cureus. 2024;16(3): e56081. doi: <u>https://doi.org/10.7759/cureus.56081</u>
- [5] Alattar N, Felton A, Stickley T. Mental health and stigma in Saudi Arabia: a scoping review. Ment Health Rev J. 2021;26(2):180–196. doi: <u>https://doi.org/10.1108/MHRJ-08-2020-0055</u>
- [6] Hargreaves S, Bath PA, Duffin S, Ellis J. Sharing and empathy in digital spaces: qualitative study of online health forums for breast cancer and motor neuron disease (amyotrophic lateral sclerosis). J Med Internet Res. 2018;20(6): e222. doi: <u>https://doi.org/10.2196/jmir.9709</u>
- [7] Sanger S, Duffin S, Gough RE, Bath PA. Use of Online Health Forums by People Living with Breast Cancer During the COVID-19 Pandemic: Thematic Analysis. JMIR Cancer. 2023;9: e42783.
- [8] Gu D, Li M, Yang X, Gu Y, Zhao Y, Liang C, et al. An analysis of cognitive change in online mental health communities: A textual data analysis based on post replies of support seekers. Inf Process Manag. 2023;60(2):103192. doi: <u>https://doi.org/10.1016/j.ipm.2022.103192</u>
- [9] Xu K, Li X. Complaining, regret, superiority, and discovery: Chinese patients' sense making of depression in an online forum. Qual Health Res. 2023;33(7):613–623.
- [10] Bobicev V, Sokolova M, El Emam K, Jafer Y, Dewar B, Jonker E, et al. Can anonymous posters on medical forums be reidentified? J Med Internet Res. 2013;15(10).
- [11] Braun V, Clarke V. Thematic analysis: a practical guide. Clarke V, editor. Los Angeles: SAGE; 2022.
- [12] Braun V, Clarke V. Reflecting on reflexive thematic analysis. Qual Res Sport Exerc Health. 2019;11(4):589–597. doi: <u>https://doi.org/10.1080/2159676X.2019.1628806</u>
- [13] Haddad PM. Do antidepressants cause dependence? Epidemiol Psichiatr Soc. 2005;14(2):58–62.
- [14] Alaraifi RA, Almusailhi JA, Alanqari SA, Alfaqeer AF, Alzamil NA, Sairafi SN, Alibrahim NR, Alghamdi KS. Awareness of uses and side effects of antidepressants and their association with depression and social stigma among adolescents in Saudi Arabia. Australas Med J. 2022; 15:399–404.
- [15] Zhao Y, Da J, Yan J. Detecting health misinformation in online health communities: Incorporating behavioral features into machine learning based approaches. Inf Process Manag. 2021;58(1):102390.
- [16] Bizzotto N, Schulz PJ, de Bruijn GJ. The "Loci" of Misinformation and Its Correction in Peer- and Expert-Led Online Communities for Mental Health: Content Analysis. J Med Internet Res. 2023;25: e44656. doi: https://doi.org/10.2196/44656