

Dementia and Technology

“We see you. We feel you.”: Motivations and impacts of sharing about dementia on social media

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Purpose An increasing number of people living with dementia and their care partners are turning to social media platforms to seek advice, access information, share personal stories, and connect with others for support. A recent study of dementia-related posts on social media uncovered several hundred thousand posts over the course of a single year [1]. This engagement often involves the disclosure of a dementia diagnosis or identification as a care partner, a practice that carries both potential risks and benefits. Social media use has been shown to foster community connections, which in turn influences the mental and physical health of people living with dementia and their care partners. However, significant concerns remain regarding the potential risk of exposure to misinformation and stigma as a result of self-disclosure. The current project aims to explore the underlying motivations and potential impact of self-disclosure on social media. **Method** We performed a content and thematic analysis of public social media posts obtained from Facebook and Reddit, consistent with prior work [1-3]. A total of 22,101 posts related to self-disclosure were retrieved from 36 Facebook groups and pages over a six-month period. Of these, a sample of 1,621 posts were selected for final coding and thematic analysis. For Reddit, a total of 1,032 posts were retrieved, with a final sample of 779 posts retained after applying exclusion criteria. To gain deeper insights into exchanges surrounding dementia, comments and replies to 153 Facebook posts and 187 Reddit posts were also analyzed. A coding guide was iteratively refined by two coders until intercoder reliability reached >80% and then applied to the final sample of posts in the sample. **Results and Discussion** Preliminary findings indicate advice- and information-seeking as the predominant motivations for self-disclosure, with users frequently requesting personal experiences and insights into complex symptomology. A response analysis revealed that the majority of Facebook users either provided information, including advice, or related to the original poster's circumstances. Initial thematic analysis identified key themes, including complex and iterative grief, challenges associated with end-of-life decisions, and the compounding nature of functional decline. The insights uncovered in this work can inform safer social media practices for people living with dementia and their care partners as well as the development of evidence-based guidance resources to support decision-making around social media use for this community.

References

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Keywords: Dementia social media, self-disclosure, support, eHealth

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