A Grounded Theory and Collaborative Design Approach to Disability Storytelling on TikTok

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ABSTRACT

This developing dissertation explores the use of TikTok as a platform for individual and collective storytelling and information creation practices – within a specific online health community of people experiencing painful, invisible, and difficult to diagnose central sensitivity syndromes (CSSs) – to understand and support these embodied, creative, and collective information behaviors. Ongoing data collection indicates that people with CSSs are using TikTok affordances to tell and scaffold complex micro-stories about their expertise and social experiences of disability: by employing iconographic elements to make disability visual; intimate cinematography; audio, visual, and community-specific mimetic options; and platform-specific novel feature use.

The research design draws upon critical disabilities studies (CDS) sensitizing concepts. A constructivist grounded theory approach will be employed, by theoretically sampling TikTok micro-videos, their top comments, and, by the time of this presentation, conducting semi-structured interviews with CSS TikTok community members. This poster also discusses these preliminary results, as well as a novel initial sampling approach which addresses both the hashtag and algorithmic logics of the platform, and an implementation of feminist ethics of care in research methods.

Then, three codesign workshops with individuals experiencing CSSs will develop creative storytelling materials that can be utilized in various contexts. These workshops promote the inclusion of disabled community members as co-designers and aim to co-design physical and digital storytelling resources such as prompts, templates, and TikTok features. These findings expand storytelling theory into the health domain, introduce and define algorithmically mediated online health communities, and promote critical disability studies perspectives in information science.

ALISE RESEARCH TAXONOMY TOPICS

Information needs; Information seeking; Specific populations; Community engagement; Social media

AUTHOR KEYWORDS

storytelling; disability and information technology; TikTok; health information behaviors; critical disability studies; participatory research methods