Welcome to #SpoonieTok: understanding and supporting disability expertise storytelling abilities and collective information practices on TikTok and beyond

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ABSTRACT

This work-in-progress poster reports on late-breaking and developing findings from interlocking dissertation research projects on individual and collective storytelling and information creation practices in chronic illness TikTok communities, with the ultimate goal to support these embodied, creative, and multimodal abilities on and off-app. Findings from ongoing data collection and grounded theory coding, from an initial sampling of 150 TikTok videos and their top-20 comments, include folks' sharing of 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.

Disabled creators on TikTok engage in what I call algorithmically-mediated online health communities, which have slippery boundaries where information can be found serendipitously through algorithmic ranking, and people connect across specific illness categories within chronic illnesses. Interviews with 11 community members further illuminate through discussion of motivations and communication-skill benefits, and visualizing activities to 'map' the individuals' communit(ies) and in-app experiences. These explain at more depth how disabled creators actively create 'disabled expertise' and information in embodied (dance, gestures), collective (audio meme variations; scaffolding patient expertise in comments), affective (private-made-public anguish), and complexly multimodal ways (cinematography, CapCut templates, trends)—and how each of these dimensions make disability-specific storytelling easier, more enjoyable, or more effective. This work-in-progress is developing a set of disability-specific storytelling abilities, which interview participants indicate are transferable to off-app settings; and upcoming codesign workshops collaborating with current community members and non-TikTok users will further distill storytelling support needs.

ALISE RESEARCH TAXONOMY TOPICS

information needs; information seeking; specific populations; community engagement; social media.

AUTHOR KEYWORDS

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