CANCER ON TIKTOK–EVALUATING ONLINE SELF-DISCLOSURE USING DIRECTED CONTENT ANALYSIS AND IN-DEPTH INTERVIEWS

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Introduction

TikTok, a social media app featuring short video content, has become immensely popular around the world (Zeng et al., 2021). Some researchers claim social media are more about the "positive culture" (e.g., Lee-Won et al., 2014), which means that content with a positive tone is more desirable and accepted than that with a negative one and users want to present themselves without undesirable traits. The study focuses on TikTok videos by users with cancer and their experiences.

The research continues the work done by the first author (Pluta, 2021) on online self-disclosure of women with breast cancer using Instagram, with self-disclosure understood as the willingness to provide intimate, private information about oneself (e.g., Barak & Suler, 2008). Previously, Pluta showed that Instagram posts are full of fears, anxiety, pain, weaknesses, and suffering associated with the treatment and body changes (C1: Category 1–self-disclosure of negative information). Importantly, the posts also turn out to be a form of self-therapy. Instagram narratives relate to positive emotions, joyful life events, self-acceptance, self-affirmation, education (e.g. prevention, debunking stereotypes about cancer) (C2: Category 2–self-disclosure of positive information), and people supporting them on their way to recovery (C3: Category 3–disclosure of information about other people). However, this previous research revolved around the posts, and thus was limited when concluding about the experiences of the users.

The presented paper aims to characterize TikTok practices of users with cancer considering positive culture and online self-disclosure. The researchers ask the following questions: 1) are TikTok videos disclosing information in the manner the previous research on Instagram shows? This question–despite being a yes/no type of question–is intended to compare different platform cultures (Instagram vs TikTok) for specific use practices. At the same time, the study asks 2) what are the creators' motivations and what meanings they give to disclosing cancer–are these in line with what one can see on TikTok? How do the users position themselves considering the social media positive culture; does disclosing cancer debunk or support this culture (or both to some extent)?

Methods

Combining qualitative directed content analysis (DCA) with in-depth interviews (IDI) is crucial here. Stage 1 of the research was about analyzing the content using hashtags to identify and sample the most relevant profiles and videos posted. 862 videos from four profiles were analyzed and the profiles were chosen based on the list that included the number of followers, likes, and videos for each profile. DCA was used as described by Hsieh & Shannon (2005). It is especially appropriate for research aiming to describe further a given phenomenon as the previous study would benefit from expanding and also offering supporting and non-supporting evidence for a given study. Also, this approach is deductive and guided by a more structured process than a conventional approach. Thus, the codebook was developed based on prior research on Instagram (Pluta, 2021) with previously identified categories and subcategories (the three categories indicated above and 10 subcategories).

Stage 2 (guided by stage 1), i.e., semi-structured online IDIs (n=8) was intended to go beyond DCA to a more nuanced understanding of the users' lived experience. To sample the respondents, the previously indicated list of profiles was used. Eight people were reached and interviewed, including the creators of four analyzed profiles, and sample saturation was successfully achieved. The research was conducted under all ethical standards (see e.g., Elgesem, 2015).

Findings and relevance

Similar to Instagram, TikTok is a tool for negative (C1) and positive online self-disclosure (C2) and disclosing others (C3). DCA revealed that content on TikTok is much more positive (C1 being 24 percent of all videos; C2–79 percent), and the videos are mostly educational (see IDIs below). C3 is not numerous (8 percent of all videos), which does not mean that there are no such videos at all. Also, some new Categories (and Subcategories) were indicated–e.g., responding to hateful comments (see below) and raising money for treatment.

The interviews confirmed that the respondents want to educate others, as they feel especially competent because of their experiences. For them, TikTok is not about getting support, but a tool to inform and warn others. The interviewees pointed out TikTok's informal rules, including using trends (e.g., Herrman, 2019), which means that videos are usually more positive despite dealing with a difficult topic. However, this does

not mean that there is a positive culture understood as presenting oneself without any undesirable traits (e.g., Lee-Won et al., 2014). The respondents seem not to care how they are perceived while disclosing cancer. Especially since some of them get unfavorable comments about being a "cancer celebrity"–these are mostly ignored or mocked. Here positive culture means more content with a positive self-disclosure as it has been previously defined (e.g., joyful life events, self-acceptance, self-affirmation).

Similar to the previous Instagram study, the research presented here undermines the traditional understanding of online self-disclosure. Previously anonymity and lack of support from close others (e.g., friends or relatives) were debunked as conditions necessary to disclose oneself. This study on TikTok shows that one may even not seek support from other social media users (e.g., Barak & Suler, 2008). It is not that creators do not want to receive support, but what they want most of all is to educate others and this is a crucial part of their experience. Also, the study shows that positive culture is not a general category, as particular social media are internally diverse and the users constitute different niches, with different content addressed to different audiences.

The work is important for several reasons. 1) TikTok (and social media in general) is so far rarely explored as a field of activity for people with chronic illnesses. 2) Existing studies on TikTok focusing on content analysis lack an even deeper qualitative approach and the paper provides this depth through the use of IDIs. Also, 3) the study deepens our understanding of how and why people use social media in general and shows that this usage has many, often unexpected, facets.

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