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## COMMUNICATING CARE: HEALING, THERAPY AND INFLUENCER PRACTICES ON SOCIAL MEDIA

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Internet cultures have long offered citizens the opportunity to connect, share information and collectively 'make sense' of health and life challenges. Early digital forums, e-lists, blogs and webpages enabled grassroots participation for people and communities with lived experience to expand how, where and when people talked about disabling, stigmatising and confusing health experiences and conditions. The internet's revolutionary potential for health-related communication has been tracked by media scholars and others who demonstrate its varying capacity to make living with health challenges more visible, archivable and collectively mediated (e.g., Orgad, 2005; Rheingold, 1994). These practices endure as digital technologies shift and develop; sharing one's health experiences with others remains a familiar theme across social media platforms. For example, recent scholarship demonstrates how social media afford different bodily narratives or visibility (Schreiber 2023; Vicari 2021; Groenevelt et al., 2022), and reprieve from the mundane daily challenges of negotiating mental illness and keeping up with one's friends (Hendry, 2020). Much of the labour to communicate care, experience-produced knowledge and community with others is taken up by health (micro-)influencers and content creators. We suggest that these figures fill the gaps of medical health systems that, within the global north, typically offer 'care' that denies agency, control and participation led by lived experience.

Building on two case studies, this paper will discuss emerging healing and therapy cultures on social media and the role of (micro-)influencers. While influencer cultures have become an important field of internet research over the last decade (see e.g., Abidin, 2015), scholars typically focus on commercial influencers in the context of fashion, beauty, travel, lifestyle genres, and adjacent genres. Moving beyond this focus, the TikTok Research Network has recently identified 'social justice influencers' as an emerging phenomenon mainly in political and activist contexts (Abidin & Jin, 2022),

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drawing on earlier social justice digital practices on platforms such as Tumblr and Reddit (e.g. Tiidenberg et al., 2021).

This paper contributes to extending how we imagine and theorise influencer practices and explores influencers and influencer practices that are motivated, arguably, by *healing* rather than financial or ideological ambitions. Theoretically, we consider how digital affect cultures enable influencers and followers to (re)create narratives about health, relate through resonance and engage with media as rituals rather than merely transmit information. As influencer practices and cultures continue to expand beyond popular or normative conceptualisations, this paper offers empirical accounts as a starting point to open up the contexts and theories we use to explore influencer dynamics.

## **Case studies**

Our first case study builds on an online ethnography of #strokesurvivor on Instagram. including interviews and close readings of accounts of contributors who emerged as micro-influencers within this specific community or hashtag public. The more 'experienced' or less affected survivors feel responsible or even 'called to' support others. On Instagram, they usually do not share scientific or medical information but focus on (visual) storytelling of their personal recovery process and how they overcame (or not) obstacles and challenges. The narratives they offer vary; they are entangled with different styles of content creation but even more so with different modes of adapting and coping with their strokes, which may resonate with different audiences. They are active in the community and often comment on others' stroke posts and are regularly mentioned and tagged. But becoming connecting nodes in this networked public also entails stressful expectations regarding their exposed position. They are consulted for advice or peer mentoring through platform comments and private messages; answering those generates time-consuming unpaid labor. Overall, they typically become influencers by accident then later develop professionalism that goes beyond their Instagram accounts as they start writing books or hosting podcasts.

Our second case study focuses on audiences, followers, listeners and "lurkers" of mental health-related influencers, podcasts and content creators. In this digital ethnography project, young adults (ages 21 to 40 years) in Melbourne, Australia, who were clients of psychologists, counsellors or other therapists, were interviewed over a series of interviews in 2021 and 2022. The project explored how they use social media in relation to their mental health experiences. Participants learned and adopted norms, values and habits through their social media practices to embrace, consider *and* challenge normative ideas about mental health and therapeutic cultures that champion popular psychological tropes towards self-development and emotional control (e.g., Salmenniemi et al., 2019). *How* influencers, podcasters and other content creators communicated in familiar, timely or 'resonating' modes was more important than *what* ideas or information were circulated.

## Theorising health-related influencer practices

Other scholarship demonstrates how health influencers emerge in different ways. On Twitter, for example, they act as curators of (scientific) information and sources. Users whose messages are frequently retweeted and whose handles are mentioned often become gatekeepers of public issues (Vicari, 2021). In anonymous mental health groups, users become health influencers who are peer mentors and role models through their intensive engagement, non-professional expertise, and authority (McCosker, 2018). In self-help communities, people with a problem tend to help other people with similar challenges, which is often (more) beneficial for those *giving* the help — the helper therapy principle, a well-known pre-internet phenomenon (Riessman, 1965). Moreover, becoming a "wounded storyteller" can become a way of recovering one's voice, because "as wounded, people may be cared for, but as storytellers, they care for others" (Frank, 2013, p. xx).

This shift is not only an act of empowerment regarding one's *narrative* but also establishes a relation of care. We understand care as an affective, cultural practice, that "enables us to move beyond the individual actor and the embodied emotion perspective and understand emotion in a larger framework as something that people do." (Döveling et al., 2018, p. 2). Within this "*digital affect culture*", the notion of alignment and belonging is crucial as such a culture "transmits emotions of solidarity and where ritual performances and participation in them are contextually normalized" (ibid. p. 7).

We engage with belonging in the context of care and healing through Hartmut Rosa's (2019) theory of resonance. He suggests *resonance* as a form of connection in alienated late-modern societies, describing it as "a mode of relating to the world in which the subject feels touched, moved or addressed by the people, places, objects, etc. he or she encounters" (pp. 46–47). While he focuses on offline encounters, he understands mediated content to afford experiences of resonance, as users "expose themselves to narratives because this helps them to come to terms with themselves and with their relationships with others and the world" (Vorderer & Halfmann, 2019, p. 88f.). Engaging via resonance can become habitual throughout the healing process, constituting a ritualistic form of media use. This approach draws on James Carey's (2008) concept of media communication as *ritual* that, in contrast to information transmission, builds culture through media engagement over time.

Together, the two case studies attend to different perspectives — from (micro-) influencers *and* audiences or followers — of health-related digital affective cultures. While these case studies are empirically distinct, we offer them as a way to open up conversation at the conference about the diversity of influencers and influencer culture, how we might theorise their role, and how care, healing, health and therapy are felt and communicated.

## References

Abidin, C. (2015). Communicative Vintimacies: Influencers and perceived interconnectedness. *Ada: A Journal of Gender, New Media, and Technology, 8.* <u>http://adanewmedia.org/2015/11/issue8-abidin/</u></u>

Abidin, C., & Jin, L. (2022). Social justice through social media pop cultures: Case studies and reading resources on influencers and TikTok. TikTok Cultures Research Network (TCRN) & Social Media Pop Cultures Programme, Centre for Culture and Technology (CCAT), Curtin University.

Carey, J. (2008). Communication as culture (Revised ed.). Routledge.

Döveling, K., Harju, A. A., & Sommer, D. (2018). From mediatized emotion to digital affect cultures: New technologies and global flows of emotion. *Social Media* + *Society*, 4(1), 1–11.

Frank, A. W. (2013). *The wounded storyteller: Body, illness, and ethics* (2nd ed.). The University of Chicago Press.

Groenevelt, I., Haan, S. de, & Slatman, J. (2022). Doing bodies in YouTube videos about contested illnesses. *Body & Society, 28*(4), 28–52.

Hendry, N. A. (2020). Young Women's Mental Illness and (In-)visible Social Media Practices of Control and Emotional Recognition. *Social Media* + *Society*, *6*(4), 1–10. <u>https://doi.org/10.1177/2056305120963832</u>

McCosker, A. (2018). Engaging mental health online: Insights from beyondblue's forum influencers. *New Media & Society, 20*(12), 4748–4764.

Orgad, S. (2005). Storytelling online: Talking breast cancer on the internet. Peter Lang.

Rheingold, H. (1994) *The virtual community: Finding connection in a computerized world.* Secker and Warburg.

Riessman, F. (1965). The "helper" therapy principle. Social Work, 10, 27-32.

Rosa, H. (2019). *Resonance: A sociology of our relationship to the world*. John Wiley & Sons.

Salmenniemi, S., Nurmi, J., Perheentupa, I., & Bergroth, H. (2019). Assembling therapeutics: Cultures, politics and materiality. Routledge.

Schreiber, M. (2023). #strokesurvivor on Instagram: Conjunctive experiences of adapting to disability. *MedieKultur: Journal of Media and Communication Research*, 39(74), 50–72. <u>https://doi.org/10.7146/mk.v39i74.132468</u>

Tiidenberg, K., Hendry, N. A., & Abidin, C. (2021). *Tumblr*. Polity Press.

Vicari, S. (2021). *Digital media and participatory cultures of health and illness*. Routledge.

Vorderer, P., & Halfmann, A. (2019). Why do we entertain ourselves with media narratives? A theory of resonance perspective on entertainment experiences. *Annals of the International Communication Association, 43*(2), 79–96.