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HEALTH CREATOR: ANATOMY OF A FUZZY CONCEPT

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Panel Introduction

“Health creator” is now a common term across academic work (e.g., Avella, 2024) and public parlance (e.g., Moore, 2020), also featuring in the title of one of the traditional panels at AoIR2024. However, as a label, it directs our attention away from matters of *ill* health (e.g., suffering, diagnosis, loss, treatment, struggle), overlooking the work of those who create content based on first person accounts of illness and missing the multiple implications this work has for creators, audiences and wider publics. As a concept, it remains underdeveloped– even despite the growing body of both academic research on platform economies and creator cultures (e.g., Cunningham and Craig, 2021) and global policy work interested in the influence of social media practices on lay and public understandings of health and medicine (e.g., WHO, 2025).

The panel aims to shed light on the wider spectrum of creator work that draws on matters of health, illness and care and develop a conceptual toolkit to interpret this work, understand its labour and explore its implications. To achieve this goal, the panel reviews evidence of lived experience, epistemic work, credibility, and influence in the context of relevant social media practices. It does so through five case studies approaching creators and their content on and through a range of platforms, namely, Facebook, Instagram, X, TikTok, YouTube, BlueSky and LinkedIn. To provide a comprehensive account of the processes through which content is created, shared, and audienced, the panel explores all sites of meaning making: it starts by focusing on creators themselves (paper 1), to then draw attention to content (paper 2 and 3), platform structures (paper 4), and audiences (paper 5).

Paper 1 investigates how hereditary cancer **creators** across social media navigate value systems related to attention, engagement and reach. Based on findings from 57 semi-structured interviews with content creators, the paper discusses the entanglements of lived experience and platform imaginaries. This unveils an alternative scenario of creator economies, based on values of community, truth and “modular visibility”.

Paper 2 explores breast cancer vlogging **content** as a unique genre and investigates its role in processing one’s breast cancer experience. Drawing on a content analysis of 90 YouTube vlogs by 13 creators, it demonstrates creators’ platform expertise and production efforts. It also discusses evidence of the vlogs’ value as forms of crucial support and community building in navigating a breast cancer diagnosis.

Paper 3 turns to #ADHD **content** to understand how creators vernacularly conceptualize the condition and how this sits in tension or alignment with official diagnostic criteria. Drawing on a 3-year-long digital ethnographic study on Facebook, Instagram, and TikTok, the paper concludes that creators conceptualise ADHD as a behavioural, emotional or biological disorder, “rupturing” medical definitions.

Paper 4 compares cancer and ADHD creator work to assess the risks of online harms brought by accessing related content on TikTok. It does so by drawing on an ethnographic account of how videos were algorithmically recommended by the **platform** over a four-week period. It concludes that risks are mainly related to the platform’s technological affordances, short video format and monetization.

Paper 5 explores how mental health creators and their content are perceived by their **audiences**. The paper draws on a combination of interviews and auto ethnographies with 98 young adults in Estonia, Austria and the UK. It argues that trust of mental health discourse is enacted via the perceived positionality of the creator, through the lens of perceived sincerity, viewer’s feelings and content rhetoric.

In combination, these five papers cover a rich selection of case studies on the way social media creators and their content engage with matters of both health and illness. Together, they provide the unique opportunity to explore how these creators navigate, and adapt, conventional creator economies, how their content matters to patient experiences and medical taxonomies, how platform structures shape persuasion and harm and how audiences construct credibility. Extended abstracts for all five papers are included in the submission.

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ON SHARING ILLNESS CONTENT: AN ALTERNATIVE SCENARIO OF CREATOR ECONOMIES

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Introduction

Digital scholarship interested in social media practices related to sharing lived experiences of illness (e.g., cancer) has provided comprehensive insight into what is shared (e.g., Hodson and O'Meara's, 2023; Myrick et al., 2016) and why (e.g., Pluta and Siuda, 2024, Stage et al., 2020; Wellman et al. 2023) through these practices. However, we do not know much about how the users sharing this content navigate value systems related to attention, engagement and reach. We address these gaps by conceptually approaching these users as a specific type of creators, which we label here as "health and illness creators" and by mobilising research into socio-technical imaginaries.

Theoretical framing

Creators tackle issues of visibility (Duffy and Meisner, 2023), moderation (Zeng and Kaye, 2022) and harassment (Meisner, 2023). They do so through their "platform imaginaries", namely, through their understanding of "platform algorithms, interfaces, data infrastructures, moderation procedures, business models, user practices and audiences" (van Ess & Poell, 2020). Health and illness creators share personal information that can be both powerful and stigmatising and they do so in a way that is not private (see also Duguay 2022). Their content includes high degrees of self-exposure that is often meant to produce positive outcome (Pluta and Siuda, 2024) but is also particularly vulnerable to cultural narratives of ableism (Tembeck, 2016), regimes of shame (Frohlich and Zmyslinski-Seelig, 2016; Philpot et al. 2022; Rademacher, 2018) and gendered notions of sexuality, responsibility, physical attractiveness and body propriety (Vicari, Ditchfield and Chuang, 2025). In fact, the affective dimension of social media communication (Papacharissi, 2015) leads to such creators experiencing platforms as both "hope seeking technologies" (Hodson and O'Meara, 2023) and spaces for "ugly media feelings" (Stage et al, 2021). Taken all these factors together, we argue that health and illness creator work provides a unique context both to understand the labour of sharing illness content and to nuance existing understandings of platform imaginaries and creator economies. We ask:

How do health and illness creators understand platforms?

What do these understandings– and the related imaginaries– tell us about the values mobilised in their work?

To address these questions, we draw on a larger project about hereditary cancer syndromes. Diagnosed via gene testing, these conditions derive from genetic mutations that increase the risk of different types of cancer (Cancer Research UK,

2025). Unaffected carriers are often addressed as ‘previvors’ (FORCE, 2025): healthy individuals coping with the awareness of having a genetic predisposition to cancer. Existing scholarship has explored the role online spaces play in sharing and learning about these conditions (Allen et al. 2020; Finer, 2016; Authors, 2017 and Wellman et al. 2023). However, no research has investigated how those posting about hereditary cancer imagine and shape their creator work.

Data and Methods

The paper draws on data from 57 semi-structured interviews with English speaking hereditary cancer creators across two conditions, BRCA and Lynch Syndromes. Along with surveillance, especially for the early detection of colorectal (Lynch Syndrome) and breast cancer (BRCA), carriers are recommended prophylactic surgeries to prevent breast (BRCA), ovarian (BRCA, Lynch Syndrome) and endometrial cancer (Lynch Syndrome) (Cancer Research UK, 2025). Therefore, addressing these conditions offers unique potential to explore a diverse range of lived experiences of previvorship and survivorship against normalised narratives of cancer and care.

We identified creators based on a 12-month data collection of relevant public content from Instagram, Twitter, Facebook and TikTok (1 May 2022 - 30 April 2023). To increase diversity, we also shared our recruitment messages via the project social media and relevant private Facebook groups and organisation newsletters. Interviews took place online between May 2024-February 2025, involving participants from five countries, aged 25+, with experience of creating hereditary cancer content on Instagram, Facebook, TikTok, Twitter, BlueSky, LinkedIn or a combination of them. We designed the interview schedule in a way to encourage participants to share both their life-long experience of using social media and their practices as hereditary cancer creators. To ease a conversation that could tap into platform imaginaries, we used prompts around their understandings and practices related to privacy, moderation and algorithms. We targeted these and their related affordances because of their explicit relevance to lived experiences of illness (privacy), gendered expectations and regimes of shame (moderation), and visibility (algorithms, moderation), but also as a starting point to expand into wider dimensions of platform imaginaries. We analysed data via a combination of inductive and deductive coding for thematic analysis.

Preliminary findings

The platform imaginaries of health and illness creators are closely entangled with their lived experience: how illness stories are shared is not separate from how platforms are imagined. In our study, the “biographical disruption” (Bury, 1982) brought by the genetic mutation, and by the evolving relational networks and sense making that emerge because of this disruption, shape the way creators imagine platforms and organise their work. Understandings of privacy and privacy affordances, for instance, shift over time, based on the evolving of the condition and the emotional and material resources mobilised for it. For these creators, platform imaginaries are, therefore, not only the result of “negotiations between multiple stakeholders” (Richter and Poell, 2023), they are also transient and biographically

evolving. Three values emerge as central to these imaginaries: of community, truth and modular visibility.

The complex labour of creating content about hereditary cancer is often shaped through the lens of *being responsible to the community*. Our participants expressed strong feelings of responsibility towards circles of peers, and this is often reflected in the way they tailor content in mirroring online spaces (e.g., the “surgical menopause group”, the “deep flat group”. Anna, Facebook creator). This resonates with “curating hope” for self and others (Hodson and O’Meara, 2023) but also discloses strong entanglements between situated experience, platform-specific imaginaries and creator work.

Curating truth emerged as a second key value. Many spoke of the importance of exposing “authentic” experience (Kat, TikTok creator), for instance to downscale “toxic positivity” (Thea, Instagram creator), silence mis/disinformation (Ellie, formerly Twitter, now Bluesky creator) or counter platform moderation, e.g., on nudity (Thea, Instagram creator). This also manifests in the goal of helping others imagine the unimaginable. Like posting a bikini selfie exposing a stoma bag, because it will reach “the greater viral” and make others see “a real living human being who has this thing that maybe a lot of people can’t imagine” (Thea, Instagram creator).

Community and truth are closely related to the value of *building modular visibility*. These creators often have a clear sense of the audiences they can reach and what they want to achieve through this reach. But they are also aware of the potential backlash of exposing personal content that is traditionally understood as private (e.g., illness), nonconventional (e.g., a flat chest on a female body), or particularly ugly (colorectal cancer, a stoma bag). So, they modulate visibility based on experienced or expected harmful commentary.

In this paper, we argue for the importance of exploring illness-focused social media sharing as a specific instance of creator work. By unpacking the biographical entanglements in how health and illness creators imagine and approach platforms, our study nuances existing conceptualisations of platform imaginaries and unveils an alternative scenario of creator economies.

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“YOU’RE NOT ALONE IN THIS AT ALL”: DESCRIPTIVE AND CONTENT ANALYSIS OF BREAST CANCER VLOGS ON YOUTUBE

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Introduction

Part of a growing genre of YouTube vlogs, the breast cancer vlog is emerging as a media practice through which women with breast cancer document and share their journeys online. As often-extended summaries of longer periods of time with the disease or significant events in the creator's experience living with it, these vlogs adopt many of the conventions seen in other types of vlogs while forging new forms of media making that may be unique to the breast cancer experience.

There is a rich community-centered aspect to breast cancer vlogs, which may position them as complementary forms of peer-to-peer social support and as unique methods for effective coping. Vlogging about breast cancer may also hold therapeutic value (Pennebaker and Seagal 1999). Online tools such as these vlogs are important parts of patients' experience with processing and managing chronic illness (Işikman 2022; Kashian and Jacobson 2020). They can help patients to find support, community, and information in spaces they may not have access to in real life (Shetty et al 2021).

The objectives of this study are 1) to determine what types of content about breast cancer tend to be discussed in vlogs, 2) to inquire into the reasons why women choose to vlog their breast cancer experiences, and 3) to consider the potential for breast cancer vlogs to serve as an alternative or complement to peer-to-peer support, as well as a site of digital community overall. We ask, what is the role of vlogging in processing one's breast cancer experience? In what ways do breast cancer vloggers adopt conventional vlog production strategies, and in what ways are breast cancer vlogs a unique genre of vlogging?

Methods

YouTube was searched in incognito mode in November 2023, using the search terms "breast cancer vlog." Breast cancer vlog creators were identified and their video characteristics were collected. Creators were identified based on whether they produced English-language breast cancer-related videos in the last 5 years.

Reviewers collected creator information (age, location, profession, and cancer stage). They collected video titles, length, date, number of views, likes, comments, and hashtags, and noted whether videos were part of a playlist. Reviewers then assessed videos based on consumer details (sponsorships, product recommendations and endorsements), and creators' explanations and discussions of their breast cancer. Engagement levels were considered based on vlog creators' discussion with their audience, whether they commented on their experience with their audience, or asked the audience to share insights of their own. Types of content (diagnosis, surgery, or another event) were also collected. Video themes were extracted both deductively and inductively. Descriptive and content analysis was performed to assess and analyze video content and potential areas where peer-to-peer support may be provided.

Results

A total of 90 vlogs by 13 creators were included. Mean video length was 21.4 minutes (SD 9.1). Mean number of views was 266,780 (SD 534,465). Mean number of comments was 1485 (SD 3422). Hashtags were included in 35 videos (39%), the majority of which were breast cancer related. Paid sponsorships were present in 11 videos (12%). Creators promoted their own channel in a large majority of videos (80; 89%); for instance, by encouraging channel subscriptions. Where mentioned, the range of 20-29 years old was most common, followed by 30-39.

Visuals were present in 60 videos (67%); of these, 34 (57%) included images or videos of vlog creators undergoing treatment (such as receiving chemotherapy or radiation or undergoing an MRI) as well as physical features of treatment, including port scars, surgical drains, and breast contour after expander placement. A portion of videos (36; 40%) included inserted recorded clips, for instance, playing a recording of a phone call with their pathologist discussing results, or footage of entering the radiation machine.

In half of the vlogs, the creator commented on how their audience makes them feel, and in 44 (49%), the creator explained why they decided to make vlogs about their breast cancer experience, the most frequent reasons being: 1) enjoying filming vlogs, 2) wanting to build a community, 3) having a predominantly female viewership, 4) wanting others with cancer to feel less alone, 5) sharing information on surgery, and 6) providing details about signs of their recurrence. For example, one vlog creator described the process of filming and posting vlogs about her metastatic breast cancer as therapeutic “because it feels like she sat and talked to someone about everything on her mind”; this creator also referred to the viewers who have expressed that her vlogs helped them through their own experiences as making her feel like her vlogs have a purpose. It is important to her that her audience – specifically, others facing a similar diagnosis – knows they are “not alone in this at all.”

Where cancer stage was mentioned, stage IV was most common (13; 14%). 22 videos (24%) were about a new diagnosis. Chemotherapy was the predominant treatment form discussed in the majority of videos (70%); surgery in 58%, primarily mastectomy; radiation in 30%; general side effects in 71%. In over half of videos (50; 57%), creators provided a structured definition to some aspect of their treatment.

Most common themes were treatment, mental health, side effects, appearance, and family relationships. Subthemes included young age, finances, the importance of online community support, social life, fear of surgery, egg retrieval, and confidence and redefining beauty standards.

Conclusions

The use of visuals and additional recorded clips in vlogs, such as the inserted phone recordings or hospital footage, may contribute to a sense of intimacy and closeness between the creator and their audience (Berlant 2008). Such instances of additional video editing are indications of vlog creators’ platform expertise and demonstrate the production efforts behind vlog creation (Abidin 2021). However, in the context of documenting one’s breast cancer experiences, additional video editing may actually

serve to provide even more detail for one's audience, and to potentially rupture boundaries between public and private: playing a phone recording or showing hospital footage (of, for instance, receiving chemotherapy infusions) allows the audience to see and hear parts of the creator's breast cancer experience that they were not present for, thereby creating a further sense of closeness with the creator. For these creators, there is something important about sharing what tends to be considered private. The perceived closeness afforded by hospital footage and recorded phone calls, for example, may also serve to demystify these experiences for audience members who might be about to begin their own breast cancer treatment. In this context, typical conceptions of what is considered public and/or private are blurred, and viewers may begin to develop parasocial bonds with vloggers they follow (Marwick 2013; Marwick 2015; Dobson et al 2018; Hoffner and Bond 2022).

This paper demonstrates that vlogs by women with breast cancer receive significant levels of engagement and represent an important site of online community. We suggest that the potential of breast cancer vlogs to be incorporated into structures of peer support indicates their value beyond forms of entertainment to forms of crucial support and community building in navigating a breast cancer diagnosis.

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RUPTURING MEDICAL DEFINITIONS: CONTENT CREATORS' VERNACULAR CONCEPTUALISATIONS OF #ADHD

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Introduction

In recent years, social media platforms have become a large source of health information, with 56% of Gen Z users turning to TikTok for health and wellness advice (Zing Coach, 2023) from the plethora of emerging lifestyle gurus (Baker and Rojek, 2020) and wellness influencers (O'Neill, 2025; Wellman, 2023) who post on the platforms. These content creators participate in the visibility practices of creator culture, taking cues from microcelebrity practices of visibility (Senft, 2008) to position themselves as especially likeable and authentic (Hund, 2024) to appeal to viewers and grow their audiences. However, unlike other types of social media content within spheres such as the beauty and fashion industry, the creation of health and wellness content is not solely motivated by the promise of financial and/or social capital; there are large swathes of content creators who also understand their content as contributing to activist efforts of raising awareness about particular health concerns, and who are keen to forge community connections among people who share similar medical experiences (Parr and Davidson, 2008). Amongst this health and wellness social media content, posts related to ADHD have become especially prominent (Yeung et al. 2022); as of February 2025, Instagram has 5.2 million posts and Tiktok has 3.9 million posts using '#adhd'. This paper presents the findings of a digital ethnographic study into this ADHD social media content to show how ADHD content creators vernacularly conceptualize what ADHD is.

Existing Literature

Research has raised concerns regarding levels of misinformation within ADHD content (Yeung et al., 2022), and the impacts of this content on clinical diagnostic procedures (Gilmore et al., 2022; Hartnett and Cummings, 2024). Researchers are also becoming increasingly interested in the phenomenon of self-diagnosis of neurodivergence through social media content (Avella, 2023; Lupton and Southerton, forthcoming), and have demonstrated how social media platforms inform and mediate (self-)diagnosis processes while simultaneously shaping 'the sociotechnical construction of neurodivergence among youth online' (Alper et al. 2023, 11). In addition to research that examines the impact of ADHD social media content on users, there are also several studies that have analyzed the discursive strategies employed by ADHD content creators. Leveille (2024), for instance, has identified how content creators' share personal experiences and use humor to position ADHD as an identifier signifier. Similarly, Holroyd (2024) has considered

how ADHD content creators adopt various audio-visual techniques to make their videos especially believable, viewable and authoritative.

Research Question

However, despite these recent explorations, very little attention has been paid to how ADHD, as a disorder, is actually conceptualized by content creators within social media content. Namely, how are definitions, symptoms, understandings and diagnostic criteria of ADHD being discussed, (re)configured and negotiated in social media spaces to shape vernacular conceptions of ADHD and its symptomology? This paper addresses this research question by taking an inventory of the various 'vernaculars' that emerge around ADHD on social media, demonstrating how this social media content sits in tension and alignment with official diagnostic criteria, to coproduce ever-evolving social ideas of ADHD symptomology that exist alongside (and potentially rupture) official medical knowledge of ADHD.

Critical Framework and Methods

This research begins from the premise that the definitions and symptomology of disorders and illnesses are not just direct reflections of the biological, but are also contingent on their socio-cultural contexts – impacted by historical and social attitudes and beliefs, and shaped by language, technology, institutions, and the knowledge disseminated through media products (Aronowitz, 1998; Lea, 2023). As such, social media technologies and content creators can be understood as crucial actors in shaping the definitional boundaries of illness. To explore exactly how the definitions of ADHD are evolving through social media content, I conducted a 3-year-long digital ethnographic study (Hine, 2015; Pink, Postill, et al. 2015) into ADHD content on Facebook, Instagram, and TikTok. The paper draws on the content I encountered during my ethnographic emergence (including memes, short-form videos, infographics, and user captions and comments), as well as ongoing fieldnotes entries that reflect on my experience 'within the field', to provide a longitudinal, experiential and contextualized perspective of ADHD social media content. This paper specifically pays close attention to how ADHD symptomology is presented within social media content, to uncover how content creators frame and present the disorder.

Findings

Through this analysis, I find that ADHD content creators rely on the minutiae of everyday, lived experiences and embodied feelings to represent ADHD symptomology. I also find, that, among the abundance of content that present content creators' embodied and lived experiences, three prominent (and interrelated) vernacular conceptualizations of ADHD emerge, that position ADHD as either:

- 1) A behavioral disorder - This content typically highlights experiences such as 'poor time management' and 'having more than 1000 unread emails', among other quotidian experiences and behaviors, as symptoms of the disorder. In doing so, creators imply that ADHD is a disorder comprised of the inability to perform behaviors that meet particular neoliberal, institutional expectations of productivity, efficiency, organization, and self-optimization.
- 2) An emotional disorder - This shows how content creators dramatically perform embodied experiences and use editing and narrative techniques to draw attention to the feelings that they associate with ADHD (e.g. feeling stuck, anxious, overwhelmed, etc.). This content thus positions ADHD as a mode of

feeling, characterized by feelings of overwhelm, numbness, disengagement, and anxiety.

- 3) A biological disorder – This emerges through content that positions ADHD as a disorder that occurs due to innate biophysiological and neurological variation. This content typically adopts biological language related to hormones, genetics and neurology when discussing ADHD, as a way to add medical legitimacy to the content and imply that the disorder is a result of biological differentiation.

These three vernacular conceptualizations of ADHD demonstrate how understandings and definitions of the disorder are unstable and vary dramatically within social media. They also show how biological discourses, embodied experiences, and examples of everyday behaviors have become central to how content creators present ADHD and its symptomology. Indeed, many of the ADHD ‘symptoms’ and experiences presented by content creators can also be understood as quotidian lived experiences of our current neoliberal, socio-cultural context, that are being reframed by as legitimate medicalized symptoms – despite not being recognized as official symptoms or diagnostic criteria by medical professionals.

I therefore argue that by presenting such dramatically different vernacular conceptualizations of ADHD on social media, ADHD content creators make it easy for almost anyone to recognize their own behaviors and lived experiences as congruent with ADHD symptoms; when having a full inbox, feeling tired and anxious, and experiencing hormonal imbalances become indicators of the disorder, viewers can easily relate this to their own experiences, and self-identify as having ADHD. As such, contrary to previous research on online health discourse, ADHD social media content is not simply a source of advocacy, awareness, and activism. Rather, ADHD-related social media content is impacting vernacular conceptualizations of what ADHD is, expanding and rupturing the ‘definitions’ and ‘symptoms’ of ADHD proposed by medical experts, and making it possible for viewers to identify their own behaviors as symptomatic of ADHD. Health content creators are therefore playing a crucial role in determining what ADHD is at a vernacular level and shaping how people understand their own behaviors in line with these evolving definitions.

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FROM INFLUENCE TO PERSUASION: TRACING THE TACTICS AND TECHNIQUES USED TO PROMOTE CANCER MISINFORMATION ON TIKTOK AND HOW THESE DIFFER FROM #THERAPYTOK

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TikTok, the Great Radicalizer?

Health misinformation has existed for centuries with people profiting from fake miracle cures as remedies for illness and disease. Academics and medical professionals have observed a rise in health misinformation as people turn away from licensed medical experts (McKay, 2021; Nichols, 2017). The internet is central to the spread of health misinformation by making false and misleading content more accessible and lowering the barriers of entry for content creators to spread health misinformation online. Social media not only provides access to a greater volume of health misinformation; these technologies intensify the para-social relationships that users establish with those whom they follow (Horton and Wohl, 1956; Baker and Rojek, 2019).

Researchers have explored the key role influencers can play in amplifying health misinformation and conspiracy theories. For example, during the pandemic numerous influencers promoted hydroxychloroquine and ivermectin as covid miracle cures suppressed by the government and pharmaceutical industries colluding to promote vaccines (Baker and Maddox, 2022). While there is no simplistic causal relationship between viewing content and adopting misinformed or radical beliefs, influencers can play a primary role in facilitating potential radicalization pathways by exposing users to extremist content that they otherwise would not have seen and mainstreaming fringe beliefs through a gradual process of socialization.

Algorithms also render social media users susceptible to online radicalization by recommending false, misleading and extremist content. Several op-eds in the *New York Times* have criticized YouTube's recommendation algorithm for facilitating online radicalization. Journalists have reported on 'the making of a YouTube Radical' (Roose, 2019), referring to YouTube as 'the great radicalizer' (Tufekci, 2018). Researchers have explored how individual users are algorithmically steered towards more radical content on YouTube (Tufekci, 2018) with young men perceived to be particularly vulnerable to far-right content (Roose, 2019). From this perspective, radicalization is largely conceived as a technical problem.

Although radicalization is not a direct effect of consuming radical and extremist content online, TikTok's recommender algorithm has come under scrutiny for its radicalizing potential. Launched in 2016, the popular video-sharing platform in short form video content. Part of what makes the app unique is the prominence of the algorithm on the user experience (Bhandari & Bimo, 2022). The user experience on TikTok is driven by the 'For You' algorithm (Xu et al., 2019). When a user opens the app, the first thing they encounter is the 'For You Page' (FYP) where the algorithm recommends an endless scroll of popular videos, which gradually becomes more personalized as the algorithm detects patterns in the content that engages the user. The result is that users are frequently exposed to content by unknown creators and

those they do not follow. The algorithm has a disproportionate impact on TikTok users because unlike other social media apps, viewing video content comprises most of the user experience. The algorithm renders TikTok users vulnerable to consuming health mis/disinformation at a much higher rate because the algorithm connects creators with new audiences and consequently content is recommended by both those whom they follow and creators they have not chosen to follow.

Assessing Cancer Misinformation on TikTok

This paper provides an ethnographic account of how health creators present cancer cures on TikTok. Based on the findings from a preliminary study (see Baker, 2025a), it assesses the quality of cancer cure videos algorithmically recommended by TikTok over a four-week period, the radicalization pathways afforded by short video platforms like TikTok and their potential to cause online harms.

Common themes can be identified when assessing the tactics and techniques used to promote cancer misinformation on TikTok. Content creators commonly feature contrarian doctors and draw on a conspiratorial worldview to present various miracle cures as intentionally concealed and stigmatized by the establishment. This framing gives credibility to creators' claims and the cures they promote. It also presents TikTok as an independent, more reliable platform from which to access health information censored by the legacy media. Drawing on earlier cancer related research (Baker and Rojek, 2019), this paper traces a shift from influence to persuasion in how health creators promote cancer cures online (Baker, 2025a). At the same time, there are notable differences between how health creators represent physical and mental illness on TikTok and this paper explores some of these key differences regarding cancer and conditions such as ADHD on the platform (what has been more broadly described as "TherapyTok" – see Baker, 2025b).

This paper concludes by evaluating the potential risks and online harms of accessing health content on short video platforms. Since TikTok is used as a search engine by younger demographics, it becomes a key means of accessing health information online. There are several risks posed by consuming health information on TikTok: First, the technological affordances of TikTok render the app susceptible to promoting misinformation and conspiratorial content. While radicalization is not technologically determined by simply viewing content, radicalization can occur through the endless scroll of conspiratorial content algorithmically recommended to users searching for cancer cures on the platform through a gradual process of socialization. Second, short form videos can become a gateway to radical views because these videos commonly direct users to personal bios, websites and ecommerce stores. Third, online harms can be facilitated by TikTok because the app provides accessible avenues for monetization that incentivize content creators to profit from fake cancer cures. This research has important implications for content moderators because the risk of cancer misinformation is not limited to the content uploaded to the platform, but the ways in which short videos become a gateway to harmful products and more extreme, conspiratorial content.

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AUTHENTIC SUFFERING, RELATABLE STRUGGLE: MENTAL HEALTH AND WELLBEING IN AND WITH SOCIAL MEDIA

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Introduction

Discourse related to mental health and wellbeing is pervasive on social media. This serves to destigmatize mental ill health and normalize talking about it (Meriluoto 2024, Tiidenberg et al 2021). However, research has shown that references to one's mental health struggles can serve creators well within the densely populated attention economy of social media (Kanai 2018, Reade 2020, Hendry et al 2021, Wickstrom & Lind 2024). In response, audiences grow increasingly suspicious of creator's motivations when sharing mental health information, and with that their epistemic authority to speak on the matter.

In this paper we explore the complicated terrain of mental health and wellbeing related discourse on social media by focusing on how audiences perceive health creators and mental health content. Specifically, we explore users' practices of sense-making and how they perceive and assess the authenticity and trustworthiness in mental health discourse.

Theoretical framing

Online mental health discourse serves multiple functions from providing information and support to destigmatizing struggle and suffering through the emergence of peer pedagogies, therapeutic publics, non-professional expertise and various tactics of reframing both mental health and illness (Fullagar et al 2017, McCosker 2018, Byron 2019, Tiidenberg et al 2021). But talking about mental health may also have metacommunicative functions - references to one's mental health struggles can make a content creator come across as more authentic, more relatable or more trustworthy. In existing work several links have been outlined between mental health revelations and perceived authenticity and relatability. Kanai (2018) and Reade (2020) have pointed out that seeming authentic via showcasing mental health struggles or vulnerabilities often resides within and reinforces white, able-bodied, heteronormative, and middle-class identities and is contingent on striking a balance between relatable authentic struggle and revelations that will be read as too mentally ill, and their sharing as 'too much'. Hendry et al (2021) focus rather on the balance between the relatable and the aspirational; striking that balance allows creators to connect with followers on a personal level while still promoting an idealized version of health and wellness. Wickstrom and Lind (2024) address the negotiation between seeming authentic and communicating expertise. They point out that social media

influencers often assume an expert position even without the necessary credentials, but their advice and solutions hinge on buying things.

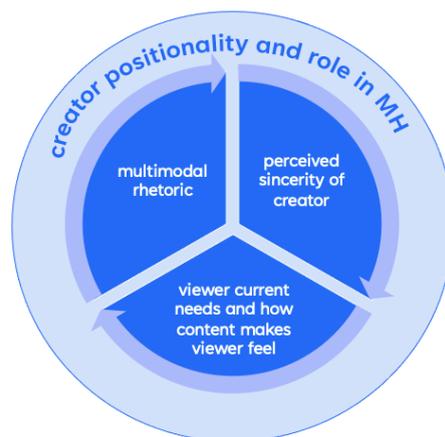
Mental health talk as enacted by social media content creators is thus complicated in several ways – on the one hand the perceived authenticity and attention received from sharing vulnerabilities invites commodifying personal struggles, on the other hand the mental health advice offered by content creators tends to oversimplify complex mental health issues, advocate self-care through consumption and commodify mental health (Wickstrom and Lind 2024). Building on existing work, we focus on how content creators’ audiences perceive mental health talk, look at what they interpret as markers of authenticity and how they experience the intersections of struggle, authenticity, attention and trust.

Method

This presentation draws on data collected as part of a larger international research project that explores the experiences and enactments of trust in visual social media communication related to everyday health and wellbeing. The arguments we make here are based on analysis of the experiences of 98 young adults (18-30) in Europe (17 interviews, 11 autoethnographies in Estonia, 40 autoethnographies in Austria and 30 interviews in UK). All of this data was coded using a project-wide coding scheme. For this paper, we pulled the data snippets coded with ‘mental health,’ ‘authenticity/inauthenticity,’ ‘relatability,’ and ‘visual trust’ and recoded them for emergent themes and patterns. These are creator positionality, perceived intentions, viewer needs and multimodal rhetoric.

Findings

We argue that trust of mental health discourse is enacted via three interrelated considerations:



First, audience perceptions about the intentions and sincerity of the creator. When participants think creators are driven by intrinsic motivations (e.g. “just wanting to help,” or sharing “because it is part of their own healing journey”) they are more likely to be considered authentic and more likely to be trusted. When they are seen as

driven by extrinsic motivations - mostly articulated as a “desperate” need for attention, or sharing “just for the sake of reach or popularity” by our participants - they are more likely to be considered inauthentic and mistrusted.

Second, the authenticity assessment is shaped by the viewer’s needs and feelings. If the content is experienced as useful or helpful – be it breathing exercises, helpful reminders, explanations how anxiety works, participants are likely to consider the advice-giver the “real deal,” and see them as authentic mental health experts. How the content and the communication make the viewer feel also importantly mediates how authentic the creator is considered, or how trustworthy their message. Content that is alarming, irritating, scary or enraging can be dismissed, whereas content that fills one with hope or inspiration may be attributed authenticity and trusted almost blindly.

This in turn brings us to the importance of rhetoric. Both in the sense of the communicated message and the chosen way of articulating and framing it. We found that authenticity assessments and trust experiences are shaped by whether the message or its delivery is found irksome in some way. For example, if the content very obviously interpellated the viewer as a customer, when they expect to be interpellated as a friend, they felt manipulated and translated that into a diagnosis of inauthenticity. If the argument is considered overly generalizing, the expertise of the content creator is likely to be questioned. Here our participants relied not only on the message content and chosen language, but also on use of visual, audio and social-media native attention-grabbing elements as evidence based on which to make their assessments.

The interrelatedness of some of these aspects is showcased in the following quote by a female British participant (29):

“I found one of his posts about mental health kind of [... annoying, yeah– or like wrong in my view because [... It was like a picture of a dark wolf and being like, ‘Oh, you just need to listen to like the light and not the dark wolf, and stuff like that. And I just found that annoying because it almost felt like victim blaming. It was almost like, oh yeah, great, all I need to do is like not listen to the wolf. Or I don’t know, it was just like making it sound more simple than it was.”

Here, oversimplification is highlighted, as well as annoying rhetoric based on a misalignment of worldviews or pre-existing beliefs. Further, we see how it makes the viewer feel, which while it does not necessarily make the creator seem insincere, it still makes their message come across as disingenuous or untrustworthy as mental health advice.

Finally, while the considerations are interrelated, we also find that they depend on or are co-constitutive with the perceived and communicated positionality of the creators within the mental health arena. How social media practices and perceptions of authenticity intersect depends on whether the creator is seen as (lay) expert for mental health, or whether they are an influencer, a celebrity or a content creator whose main focus lies elsewhere who just sometimes address the topic of mental health.

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