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Identity Roles and Sociality on TikTok: Performance in Hereditary Cancer Content (#BRCA and #Lynchsyndrome)

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Abstract

Digital platforms have long been understood as important spaces where identity performance takes place with networks and interpersonal interaction forming the basis of many theoretical approaches to self. Due to TikTok's distinctive technical structure, scholars have argued that processes of sociality and identity construction have changed, calling into question some of the founding principles of how we understand identity performance on social media. In this article, we critically engage with these debates by asking how identity is performed in TikTok content in the context of health and illness. Specifically, we explore identity performance in content on two hereditary cancer conditions: BReast CAncer (BRCA) and Lynch Syndrome, carriers of which have a much higher disposition to getting certain types of cancer in their lifetime. Through using computational data collection tools and conducting a qualitative content analysis, we find that identity is performed through the enactment of roles, all of which demonstrate how TikTok's features still enable interpersonal and networked elements of self to emerge. This article contributes to knowledge on experiences of social media and hereditary cancer by shedding light on the kinds of identity performance that become most visible through ways of sociality shaped by powerful multimodal and algorithmic platforms such as TikTok. In so doing, it also provides unprecedented insight into what content users are exposed to when seeking information and support in relation to a hereditary cancer diagnosis on TikTok.

Keywords

identity, sociality, TikTok, hereditary cancer, dramaturgy, qualitative content analysis, cancer communication, social media

Introduction

Digital platforms have long been understood as important spaces where identity performance takes place. Due to identities being "made, displayed and reshaped through interaction" (Baym, 2015, p. 119), presentations of social connections have historically been highlighted as central for identity performance on social media. Recent literature on TikTok, though, has argued that the way sociality, that is, how we interact and form social links, unfolds on the platform differs compared to that in other social media (Gerbaudo, 2024; Zulli & Zulli, 2022). These debates have been directly linked to conceptualizations of identity, with Bhandari and Bimo (2022) arguing that frameworks emphasizing social connection and interpersonal interaction may not be as relevant in the TikTok environment. These arguments call into question some of the founding principles of how we have conceptualized identity to date, with factors once positioned as central, now being downplayed due to "distinctive" platform structures such as the "For You" algorithm (Zulli & Zulli, 2022, p. 2).

In this article, we critically engage with these debates by asking how identity is performed in TikTok content in the context of health and illness. We explore social connections and interpersonal interaction by drawing on dramaturgical theory and metaphors (see Goffman, 1959). Specifically, we argue that identity is performed through the adoption of "roles"; that is, through *playing parts* and *adopting characters* in certain situations and contexts. Through conducting a qualitative content analysis on 100 TikTok videos, we find that content creators draw on various features of TikTok to perform roles, such as the *celebrator, the defender*, and *the mentor*, that demonstrate interpersonal and networked elements of self. While acknowledging the importance of work that has highlighted changes in sociality

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on TikTok, our findings have prompted us to argue that we should not dismiss the relevance and existence of interpersonal interaction and associated concepts in identity performance on this platform.

Our work draws from a project that explores social media practices in the lived experience of BReast CAncer (BRCA) and Lynch Syndrome genetic conditions, which increase the risk of developing certain types of cancer (Cancer Research UK, 2025). Carriers are recommended periodic screening to detect cancer in its early stages, and prophylactic surgeries (mastectomies, oophorectomies, hysterectomies) to *prevent* breast (BRCA), ovarian (BRCA, Lynch Syndrome), and endometrial cancer (Lynch Syndrome; see Royal Marsden NHS Foundation Trust, 2021a, 2021b). BRCA and Lynch Syndrome carriers are often referred to as "previvors" in that they have a predisposition to getting cancer but have never been diagnosed with the disease (FORCE, 2024). Of course, some carriers have been diagnosed with cancer either pre, or post, knowing of their inherited mutation through genetic testing. Existing research on hereditary cancer and social media has explored the important role online spaces play in learning about and experiencing these genetic conditions (see Allen et al., 2020; Finer, 2016; Vicari, 2017; Wellman et al., 2023). Yet, little is known about how identity is *performed* within social media posts about these conditions. That is, how features of social media platforms are utilized (or not) to construct certain dispositions and representations of self in hereditary cancer content. Asking questions about identity in relation to hereditary cancer (rather than cancer more broadly) is important, as scholars have found carriers to engage in identity practices specific to genetic risk (Getachew-Smith et al., 2020; Hallowell & Lawton, 2022). In fact, a positive genetic test is often a "metagnosis," a process through which one becomes retrospectively aware of a lifelong condition pertinent to their identity (Spencer, 2021). We extend this work by focusing on those practices in the context of social media platforms.

We do this by focusing on how identity is performed in popular TikTok content that uses hashtags associated with BRCA and Lynch Syndrome. We focus on TikTok in order to directly engage with arguments that processes of identity construction and interaction are different from experiences in other social media spaces. TikTok has also been identified as an important context to explore hereditary cancer representation specifically, with recent research indicating the potential for non-normative representations of hereditary cancer to become more visible on the platform (Vicari & Ditchfield, 2024). This article continues by exploring cancer communication, especially in relation to hereditary cancer and social media, and outlining further how existing understandings of identity performance are being challenged by the changing logics of TikTok. We then go on to present our methodological approach and research findings on three identity roles performed in hereditary cancer content. We conclude by reflecting on what our findings mean for current understandings of identity practices on social media and how these practices have implications for those seeking information and support in relation to a hereditary cancer diagnosis on TikTok.

Communicating cancer

Susan Sontag's (1978/1991) writings provide a remarkable exploration of the way cancer has historically been associated with personal traits (e.g. "someone unemotional, inhibited, respressed," p. 40) and organ-dependent regimes of shame (e.g. "lung cancer is felt to be less shameful than rectal cancer" (p. 18)). From the 1970s onwards, however, first person accounts have partially disrupted normalized means of imagining cancer (Vicari & Ditchfield, 2024; Vicari et al., 2025). In 1980, poet and activist Audre Lorde (1980/2020) wrote: "I have cancer. I'm a Black lesbian feminist poet, how am I going to do this now? Where are the models for what I'm supposed to be in this situation?" (p. 21). Lorde (1980/2020) called for breast cancer patients to exercise "militant responsibility" (p. 68) by becoming visible in the public domain, whether through voice (e.g. narrating their experience) or the visual embodiment of the disease (e.g. rejecting prosthetic interventions).

Patient accounts of illness, or "pathographies" (Hawkins, 1999), place the lived experience at the very center of the cancer narrative. Existing work discusses how they may be explicitly conceived to educate others ("didactic"), highlight deficiencies in existing systems of care ("angry"), express dissatisfaction with medicine ("alternative"), or target larger environmental, political, or cultural problems ("eco"; Hawkins, 1999). It is then perhaps unsurprising that Pluta and Siuda (2024) identify a clearly didactic purpose among TikTok cancer creators. A purpose that also clearly meets the information and support needs discussed in much research on users' engagement with social media cancer content (e.g. Hodson & O'Meara, 2023; Myrick et al., 2016).

Existing research on hereditary cancer and social media has begun to answer the questions of what hereditary cancer content looks like on social media platforms and why individuals turn to these spaces. Allen et al. (2020) and Vicari (2021), for example, show how the act of sharing information and connecting on, and about, these conditions derives from a complex combination of lay and expert sources. Vicari (2017) shows how individual patient advocates are key actors in the curation of BRCA content on sites like Twitter (now X). In terms of motivations for turning to online spaces Finer (2016) found that previvors blogged their BRCA stories to educate others, advocate for more research, and support others. Wellman et al. (2023) build on this in the platform context by highlighting how previvors feel a responsibility to share their authentic experience on social media in order to help others and mitigate their own feelings of uncertainty. What kind of information and previvor stories are visible on social media platforms, though, can vary across platforms with Vicari and Ditchfield (2024) finding different representations of hereditary cancer appearing across Instagram, TikTok, Facebook, and Twitter.

Outside of the social media context, research on hereditary cancer has made clear how testing positive for a hereditary cancer mutation produces long-term uncertainty in the lives of carriers (see Dean, 2016; Dean & Davidson, 2018). With this uncertainty, comes genetic risk management which has been understood as impacting, and being embedded within, practices of selfhood (see Getachew-Smith et al., 2020; Hallowell & Lawton, 2022). These involve the renegotiation of one's social relationships to accommodate risk-derived uncertainty in everyday life and are central to the emergence of new individualities. In other words, the awareness of carrying a genetic mutation affects how identity is constructed and understood (Getachew-Smith et al., 2020; Hallowell & Lawton, 2022). Identity construction and hereditary cancer have been explored in the context of online blogger accounts, with Ross et al.'s (2018) finding bloggers' reflections on their histories and experiences of hereditary cancer to become embedded in their sense of self.

Research on hereditary cancer and social media has not, however, explored how identity is *performed* within social media posts. In using the term performance, we draw on a Goffmanian approach to understanding identity (see 1959 work on The Presentation of Self in Everyday Life). Here, identity is understood through an array of dramaturgical metaphors which approach individuals as actors who perform self when in the presence of others. Dramaturgical theory is commonly applied in the study of identity on social media platforms (Ditchfield, 2020; Hogan, 2010; Marwick, 2013), yet has not been applied in the context of hereditary cancer identity. Applying such a theoretical lens enables us to question how individuals use the technological features of social media to craft performances of self to their audience. This goes beyond telling us *why* previvors might post on social media (e.g. Wellman et al., 2023) or how their online content becomes embedded in senses of self (Ross et al., 2018). Instead, it tells us more about the *kinds of* dispositions and representations of hereditary cancer identity that appear online. And, importantly, the kinds of hereditary cancer identities that ultimately become most *visible* on platforms governed by powerful algorithms such as TikTok.

Performing identity on social media: a dramaturgical perspective

Various terms, including performance, presentation of self and exhibition, have been applied to the exploration of identity practices in the social media context (Ditchfield, 2020; Hogan, 2010; Rettberg, 2018). The notion of identity performance is rooted in the idea that human identity is bound up with social conventions and expectations of others in that we, as individuals, desire to be perceived in particular ways (Goffman, 1959). These performances are made-up presentations (or displays): specific acts, or things people do, to perform certain versions of self (Rettberg, 2018). In this way, performances and presentation of self are very closely related, and both fall under the dramaturgical umbrella laid out by Goffman. Authors such as Hogan (2010) have utilized the concept of exhibition, rather than performance, to refer to presentations of self that happen asynchronously and through the submission of an artifact (e.g. TikTok video) to a third party "curator" (e.g. a platform with an algorithm). Although the concept of exhibition transitions well to the context of TikTok, we have chosen to utilize the term performance within this article to engage with arguments that question approaches to online identity practice such as the Networked Self—a framework that itself draws on performance and performativity terminologies (see Papacharissi, 2011, 2013, 2018).

Papacharissi's (2011) conceptualization of the Networked Self understands identities as constructed through our networks and social ties. The networked self understands social media platforms as a "stage for self presentation and social connection" (Papacharissi, 2011, p. 305). In these spaces, self presentation is achieved through utilizing communicative and technical features which, Papacharssi argues, provide props (in the form of text, photo, video, etc.) to facilitate self-presentation. In addition to utilizing props, the networked self is formed through interpersonal communication (i.e. communication between two or more people) that is adapted to an online setting. Papacharissi (2011) argues that it is this kind of interaction that ultimately enables identity expression (p. 305). Since the introduction of the Networked Self, Papacharissi (2018) has acknowledged how much has changed in relation to our networks online, noting how these are now not necessarily "organically developed" but instead "suggested" through algorithmic architectures (p. 3). In this new context, Papacharissi (2018) still argues that our identity performances are *networked* (e.g. "we perform to networks, through networks" (p. 354)) yet they may not always be *connected*. In our discussion, we reflect on this distinction in relation to illness identity performances, for which social media have been identified as important (see Boer & Slatman, 2014; Koteyko & Hunt, 2016; Tembeck, 2016).

Boer and Slatman (2014), for example, looked at how cancer bloggers made sense of the self through narrating their stories on their personal web pages. Tembeck (2016) focused on visual performance of the ill self showing how selfies on Instagram allow for autopathographic practices enabling individuals to "come out" as being "invisibly ill" (p. 6). Work investigating identity performance on social media often draws on a Goffmanian theoretical framework (Goffman, 1959). We see this in Papacharissi's work, through her use of metaphors such as *stages* and *props* and her emphasis on the importance of interactions in our identity performances. A dramaturgical approach also drives the work of Tembeck (2016), in which they note selfies to be a form of "politicized dramaturgy" enabling autopathographic practice. Plus, although not explicitly stated, Boer and Slatman (2014) draw on dramaturgical underpinnings, noting in their analysis how illness narratives are often organized on the basis of *characters* or "dramatis personae."

Recent literature on TikTok, though, has argued how the way we use and communicate on this particular platform is organized differently compared to other social media spaces (Zulli

& Zulli, 2022). Bhandari and Bimo (2022) have directly linked these debates to conceptualizations of identity, arguing how frameworks such as the networked self may not be as relevant to understanding identity in the TikTok environment. These debates are important as they call into question some of the founding principles of how we have understood identity performance to date. Factors that have once been positioned as central to processes of identity performance on social media in 2010s scholarship, such as networks, connections, and interpersonal interaction, are now argued to be downplayed by platform structures such as the "For You" algorithm (Bhandari & Bimo, 2022; Zulli & Zulli, 2022). This article critically examines these debates by exploring sociality and identity performance in TikTok's content about hereditary cancer syndromes.

Identity and sociality in the context of TikTok

Debates on the changing structure of TikTok and its impacts on how we interact and understand identity originate from the fact that TikTok has a "distinctive technical structure" (Zulli & Zulli, 2022, p. 2). The TikTok experience, unlike other platforms, is driven by the "For You" algorithm (Xu et al., 2019): an algorithm "powered by a recommendation system that delivers content to each user that is likely to be of interest to that particular user" (TikTok Newsroom, 2020). TikTok also has a different layout to older social media platforms. It still allows users to create profiles, follow accounts, comment, and send direct messages, but its emphasis is on engagement with *content*, rather than *people* (Zulli & Zulli, 2022). This is reflected in the visuality of the platform with "For You" feed videos taking up the whole screen and interactive features such as commenting and following being "relatively small icons" and "presented as secondary to the content presented by the algorithm" (Bhandari & Bimo, 2022, p. 5). These design structures have led scholars to argue that sociality, and the social experience on TikTok, is shifting (Gerbaudo, 2024), with Zulli and Zulli (2022) noting how sociality on TikTok forms "through processes of imitation and replication, not interpersonal connections, expressions of sentiment or lived experience" (p. 2).

The prominence of the "For You" algorithm on TikTok has also been the focus of much scholarship exploring identity and the platform, with work focusing on the interplay between identity and algorithmic processes (see Ionescu & Licu, 2023). Bhandari and Bimo (2022), for example, specifically complicate identity frameworks like the Networked Self by arguing that the model of the "algorithmized self" encapsulates identity on TikTok more accurately. Rather than understanding self as networked, interpersonal, and something curated from the "reflexive process of fluid associations with social circles" (Papacharissi, 2013, p. 208), they argue that the algorithmized self is about "a reflexive engagement with previous self-representations rather than with one's social connections" (Bhandari & Bimo, 2022, p. 9). TikTok users can, to some extent, "influence and manipulate" what the algorithm shows them, with the algorithm then presenting "them with access to content that reflects their own internal worlds, interests, likes and personality" (Bhandari & Bimo, 2022, p. 6). The algorithmized self is therefore about intra-connection between user and the algorithm. It's about representing yourself to the "For You" algorithm and, in turn, engaging with the representations of your inner world that it gives back to you.

Drawing on Rose's (2023, p. 47) conceptualization of the intersecting sites at which meaning is made (i.e. the site of production, of the social media post/content itself, of circulation and of audiencing), both Zulli and Zulli (2022) and Bhandari and Bimo (2022) approach the analysis of identity and sociality on TikTok from a circulation and audiencing perspective. Namely, they provide insight into platform-specific dynamics of broadcasting (circulation) and engagement (audiencing) through methods such as the platform walkthrough and interviews with TikTok "observers." In this article, we have decided to focus primarily on the TikTok content itself. Through this focus, we build on an emerging body of literature providing a counterpoint to debates arguing that older frameworks of sociality and identity performance are diminishing. Darvin (2022), for example, shows how TikTok users from Hong Kong use various semiotic resources to curate profiles, perform identities, and promote interpersonal connection, thus displaying resistance to imitation and replication logics. Quick and Maddox (2024) also highlight how logics of imitation present as secondary to (attempted) interpersonal dialogue and conversations of lived experience on political TikTok. We build on these counterpoints by questioning whether older understandings of identity performance—such as the networked self—prevail on a platform where the algorithms, and not our connections with people, are arguably prioritized. These questions are particularly important to ask in the context of illness identity, as social media platforms have been highlighted as spaces where people connect, build networks, and seek support from others who face similar situations (Myrick et al., 2016).

Methods

Data collection

This article draws on the collection and analysis of TikTok content relevant to two hereditary cancer syndromes: BRCA and Lynch Syndrome. We used computational techniques and tools to access, collect, and handle posts (i.e. data and metadata) about these conditions published on TikTok. Due to issues of inconsistency with the GitHub TikTok Scraper, we used a tool developed by the Bright Data Initiative (for more information about this, see Vicari et al., 2025). Using this tool, we collected public posts on TikTok for 15 days across the months of March and April 2023. The posts were retrieved using hashtag-based queries (#BRCA and #lynchsyndrome) and were limited to those in the English language. The data and metadata collected included details on the TikTok post's content (e.g. caption, all hashtags used), engagement metrics (number of likes and

comments), and other post details such as account handle, post URL, and the time and date stamp. The posts collected reflected what was shown on the respective hashtag page at the time of data collection. Posts displayed on TikTok's hashtag pages are ordered algorithmically (rather than chronologically). In this way, the data we collected represented content that was deemed "top" by TikTok's algorithms at the time of collection. The sample of TikTok posts used for this analysis was taken from a collection conducted on March 2, 2023. We chose this particular collection as it (1) included a large enough sample of posts to conduct content analysis and (2) was an "ordinary day" in relation to BRCA and Lynch Syndrome (e.g. no "awareness days" related to either condition).

Data analysis

We conducted a qualitative content analysis of 100 posts (the top 50 posts for #brca and the top 50 posts for #lynchsyndrome). Creators in our sample were either diagnosed with, or in the process of genetic testing for, one of these conditions themselves or had a family member who was. Some had already had a cancer diagnosis. We excluded posts from organizations and health professionals in the interest of focusing on lay, and personal, performances of identity. The same account (creator) could appear within the sample more than once because the type of identity performance did not necessarily correlate to a specific creator. In one post, a creator could perform one identity role and in another a different role.

Qualitative content analysis allows for the interpretation of content "through the systematic classification process of coding and identifying themes or patterns" (Hseih & Shannon, 2005, p. 1278). The objective of qualitative content analysis is "to capture the meanings, emphasis, and themes of messages and to understand the organisation and process of how they are presented" (Altheide, 1996, p. 33, cited in White & Marsh, 2006). This objective is particularly relevant to our work in that we aim to understand what identity elements are *emphasized* in TikTok content and how these are put together and *presented* to audiences. To begin our analysis, we constructed a coding schedule that allowed us to identify key themes and patterns in the content posted. Our coding schedule was organized into three types of codes: (1) attribute, (2) descriptive, and (3) annotative (see appendix for full coding schedule).

Attribute codes capture the basic information regarding elements such as setting, demographics, and data format (Salanda, 2016, p. 83). Similarly to the approach adopted by Krutrok (2021), we separated our attribute codes into technical and visual. Technical categories included coding the modes of communication used within a TikTok post (captions, hashtags, text and audio), the type of audio used (soundtrack, meme, or direct speech), and the more complex technical features engaged with, such as duets (a video posted alongside content from another user), comment replies (where a comment is featured on a post and the user is directly replying), or a transition (where two or more video clips are connected). Our visual codes captured what can be seen in the video such as where the video is located (home, nature, medical setting) and props engaged with (clothes, the body itself). *Descriptive* coding "assigns basic labels to data to provide an inventory of their topics" (Salanda, 2016, p. 97). Our descriptive codes capture what is *talked about* within the content. We categorized this in terms of hereditary cancer topics (surgery, common misconceptions, challenges of the condition) and social topics (sexuality, the body, gender). Attribute and descriptive codes helped us to understand *how* creators were using the multimodal features (text, audio, visuals, and technological features) to construct their identities. Drawing from techniques outlined by Serafini and Reid (2023) on conducting "multimodal content analysis," we also included the descriptions of each post in our coding to capture the "complex relationships among modes" (p. 629). We piloted our attribute and descriptive codes on a sample of 25 videos and adjusted them for consistency.

Our final type of coding, *annotation*, was less about categorization and more about making interpretative notes and observations. This is a common approach to coding in qualitative content analysis, where "memos" are used to record thoughts and develop concepts (White & Marsh, 2006). Here, we commented on the position or stance the content creator was taking in a post plus any observations we had about the kind of identity being performed. This was a significant analytical moment for us, as it was here that we noticed how our annotations were emerging as *roles*, for example, our notes were highlighting certain characters being played within the videos and certain patterns of behavior such as working to defend, celebrate, or encourage followers in various ways. After making our initial annotations, we then went back over the 100 videos and coded them as a particular "identity role." Identity roles codes were not mutually exclusive in that some videos were coded under multiple roles if a variety of performance types were present. We then mapped these roles onto our attribute and descriptive codes to identity patterns in the way these identity roles were being performed.

This research received ethics approval from The University of Sheffield in January 2022. All the data analyzed in this study were publicly shared, and popular, on social media. However, given their sensitivity and users' varying expectations of privacy, in the remainder of this article, we will use pseudonyms and draw on edited images following Taylor and VandenBroek's (2024) "penciling method." This allows for a way of retaining social media image's original context while reducing recognition to the naked eye and search engine queries. Instead of using online penciling tools to achieve this, we opted to use the GIMP software recommended by Taylor and VandenBroek (2024). In adopting this approach, we avoided uploading images onto unknown cloud platforms and could instead keep the images within our own data storage systems.

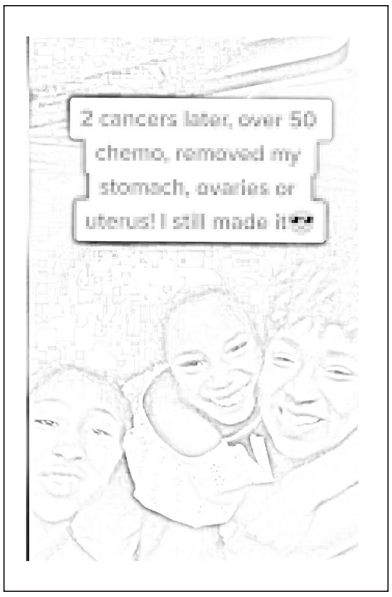

Figure 1. Amy.

Research findings

Creators play particular roles when talking about hereditary cancer. Through our qualitative content analysis, we identified the celebrator (31), the defender (23), the storyteller (23), the mentor (16), the victim (15), the documenter (13), the educator (11), and the comedian (9). Given their prominence, and the networked elements of self-manifesting in their performances, in the next sections, we will explore *the celebrator, the defender*, and *the mentor*.[1] The example posts chosen represent diversity in terms of condition (Lynch/BRCA) but also the TikTok features engaged with.

The celebrator

The most prominent role performed in TikTok's hereditary cancer content is that of the celebrator. In these posts, users work to express admiration and/or approval of themselves or others. Strength, resilience, health, and beauty are often the focus of celebration, with users constructing performances of confident, strong, and reflective selves.

Figure 1 shows Amy who has been diagnosed with Lynch Syndrome and has survived cancer twice. Amy's video begins with her sitting alone in her car with her lip syncing to a slow beat song. Video text appears here that says: "Doctor told me to say bye to my children and gave me a few months to live." A transition then happens, after which the song becomes more upbeat, Amy's children emerge from the back of the car and hug her and the video text changes to: "2 cancers later, over 50 chemo, removed my stomach, ovaries and uterus! I still made it." Here, we see Amy looking back and celebrating herself and her survival. This resonates with "transient" narratives often seen in stories of cancer where the regained lightness and normality of life are embraced (Boer & Slatman, 2014). In the context of blogs, Boer and Slatman (2014) argued that this narrative

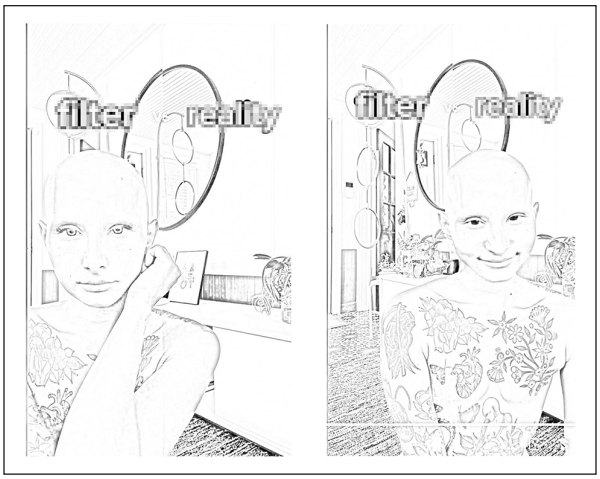

Figure 2. Mary.

was achieved through multimodal features such as a change in font, colors, and type of imagery. In this post, and many other posts enacting the celebrator on TikTok, Amy utilizes the transition feature: where two video clips are merged into one creation, a feature often used to reveal something new or signal change. Change is therefore still displayed through digital features but in ways that are more specific to TikTok's visual form. Amy's video also showcases another common pattern in celebrator content: the presence of family and friends, with her two daughters featuring in the post both textually (told to say bye to her children) and visually (through appearing after the transition).

As well as celebrating survival and resilience, it is common for celebrator content to show appreciation of physical beauty. Mary (Figure 2) is one example of this. Mary (a BRCA gene carrier) is celebrating her authentic beauty by first showing herself using an enhancing TikTok filter (the left of the shot) before transitioning to the right of the screen, where no filter was present, what Mary labels as "reality." Mary performs the celebrator through various modes of communication in her post, tagging #selfloveappreciation and using the audio of Sia "Unstoppable" to soundtrack her post featuring lyrics that highlight power, confidence, and emotional strength.

On social media platforms like Instagram, elements of "pink ribbon culture" (Sulik, 2014) have been argued to persist (Vicari & Ditchfield, 2024). Pink ribbon culture emphasizes the expectation to be "optimistic and strong" yet also "restore bodies to traditional femininity through wigs, make up, prosthetics and breast reconstruction" (La et al., 2019, p. 605). In Mary's post, we can see characteristics of presenting the self as optimistic and strong (through her soundtrack choice and appreciation of the self). Yet, Mary has foregone post-mastectomy breast reconstruction and opted for an aesthetic flat closure. She also has alopecia (she uses hashtags connected to this as well as BRCA), a condition resulting in hair loss. In celebrating her physical beauty, then, she is *not* celebrating feminine beauty in the pink ribbon sense by restoring her body to traditional femininity. Instead, through the absence of hair, breasts, and other props such as wigs and

Figure 3. Tom.

prosthetics, she is subverting the norms traditionally inscribed in the female body and is appreciating and celebrating *that* instead. In their study of "flattie" blog content, La et al. (2019) found users to conceal their flatness with clothes or accessories. Mary, though, proudly displays her flat body not only stripping herself of traditional feminine beauty props but also stripping herself of digitally enhanced beauty through the removal of a TikTok filter. In this way, Mary is disrupting meanings of (traditional) femininity and carving space for what Morena (2022) defines as "a broader (and more intersectional) range of women's experiences of mastectomy and breast cancer" (no page number).

A final example of the celebrator comes from Tom, who has a TikTok account in which he posts updates on his family life. His wife has the BRCA gene mutation and has chosen to undergo preventive surgery, including a double mastectomy and hysterectomy. Although Tom is not the BRCA carrier himself, he represents his wife and her BRCA experience through his content, thus emphasizing certain elements of her identity in relation to hereditary cancer. An example of one of Tom's posts can be seen in Figure 3. Here, he created a montage of pictures and video clips that showed his wife in hospital and recovering from her surgery, followed by images and clips of her "well self" including a clip of her running and a festive family photo. There are three layers of communication in addition to the image montage. The first is the video text that appears overlaid on the images (seen in the extract below). Second is the audio playing: a spoken clip of a male voice declaring admiration for a loved one. Third is the post's caption where Tom writes: "My wife is an absolute warrior."

> As a nurse and mom of three the surgeries were very hard on her, she didn't feel pretty, she was in tremendous pain and she felt like she was neglecting her family. As her husband, I could not be more proud of her resiliency and strength. She made a difficult decision to suffer now so she could be there for her family in the future and in my opinion, she is still the prettiest woman in the room. (Tom)

Like Amy's video, Tom's post includes images of his wife's family and friends, displaying her close family ties in both the images of the montage and the emphasis he places on her role as a mother and wife in the overlaying video text and caption *(mom of three, so she could be there for her family, warrior wife)*. Tom also works to celebrate his wife's physical appearance noting in both the video text, and audio, how beautiful she is as well as celebrating her for her strength and resilience, crediting her as a warrior. Through presenting gendered notions of responsibility to family, references to physical attractiveness and metaphors of war and battle, Tom is drawing on many facets linked to the "pink ribbon culture" (Sulik, 2014) discussed earlier. While doing this, though, this particular post also works to disrupt pink ribbon tropes of being overly optimistic and hiding painful realities (La et al., 2019) as Tom shows images of his wife ill in hospital *alongside* imagery of her well (and beautiful) self.

The defender

Receiving criticism and insensitive comments in response to telling cancer stories on social media has been highlighted as a challenge of publicly sharing cancer experiences (Stage et al., 2021). In our data, we found that creators actively worked to respond to criticism, stigma, and misconception. They did this through performing the role of *the defender*. Through this, they adopt the role of *defending* themselves, their decisions, and their wider communities, often showcasing a politicized self. An example of the defender can be seen with Jade (Figure 4). Jade sits in her car and speaks to her audience directly with no video text, other audio, or caption. Before this, she had posted a series of videos documenting symptoms she has been experiencing and how she is being tested for different cancers and genetic mutations (she tags both BRCA and Lynch Syndrome in her content as, at the time of posting, she did not know if she had a mutation or which one). Jade says:

> There have been one or two comments that are just unwanted, unneeded, and personally I don't really care about those comments. But let me tell you something, if what I'm saying scares you, then maybe it should. I was going through this stuff and had to advocate for myself and it was scary. Women's health is a huge issue, we often brush ourselves off because we're mothers, wives, daughters and we're busy and we're the ones populating the universe.

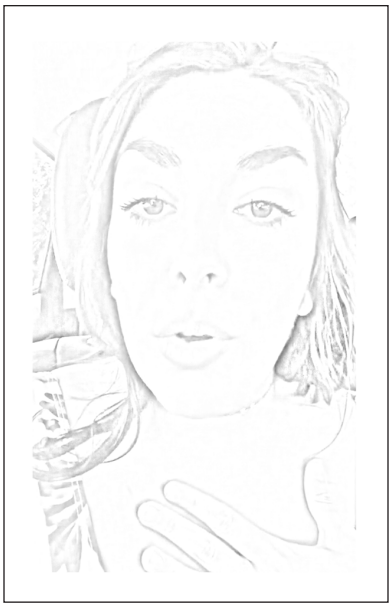

Figure 4. Jade.

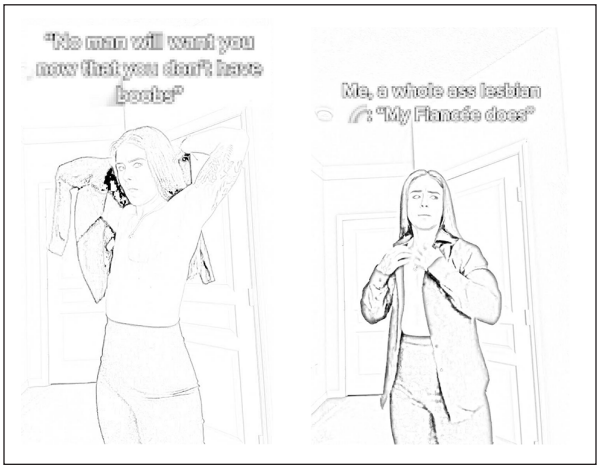

Figure 5. Sarah.

Here, we can see Jade responding to comments she has received (presumably online comments—but this is not clarified) simply through her direct speech utilizing very little of the platform features. Her performance is politicized in the sense that she performs not personally caring about this criticism but that it is important in relation to women's health more generally—linking this to gendered roles in society.

Second, we have Sarah (Figure 5) who engages in a hypothetical interaction with the imagined critic. Sarah, like Mary, has chosen not to have breast reconstruction after a double mastectomy and presents herself as part of the "flattie" community (through her use of #flattie). Here, Sarah is responding to a comment that "no man will want you now that you don't have boobs"—it is not clear if this is an actual comment Sarah received on TikTok, in real life,

Figure 6. Leslie.

or is hypothetical. She utilizes a lot more of the TikTok features compared to Jade and performs the defender multimodally—though video text—responding to this comment with "me, a whole ass lesbian: my fiance does." But also through using the lip sync function. The audio playing over these images is a sound bite that says "why do you have to go and bring that up?" Sarah lip syncs to this as she puts on her shirt.

Finally, we have Leslie (Figure 6), another flattie. She utilizes the comment reply feature (that allows users to directly reply to a post's comment) to perform her response. Here, Leslie has received a comment saying: "I see what you mean, I even thought you were a man lol. I'm sorry about you having a mastectomy. I don't condone transsexual people. Sorry." Leslie then records herself responding while applying body art to her flat chest. She talks about how, personally, she is comfortable with her identity and how she looks but that:

> There are women in the flattie groups who have talked about being misgendered. Even when it is unintentional, it can be devastating to them. I mean, it can break their hearts. So the casual "lol" attitude is so much more destructive than probably you even think it is

We can see here how Leslie breaks down the comment left to her—picking out particular discursive features (such as the "lol") and explaining that they are damaging to the community that she represents.

The defender is performed using what Ebbrecht-Hartmann and Divon (2022) have labeled as the "responsive mode" of storytelling. That is, TikTok communication that draws on communicative features to "negotiate controversial views and offer facts and contextualising information in reaction to problematic, trivialising and or distorting content" (Ebbrecht-Hartmann & Divon, 2022). The defender role shown within these three examples illustrate how a politicized identity is performed within hereditary cancer content. As previously highlighted in the work of Tembeck (2016), these examples make visible usually invisible conditions (e.g. BRCA gene mutation). This is specifically the case with Sarah and Leslie, who show their bare, flat chests in their TikTok videos. In this way, Sarah and Leslie are exercising their "militant responsibility" by visually presenting their non-reconstructed bodies to their TikTok audience (Lorde, 1980/2020, p. 68). This in itself is politicized as it engages with anti-prosthetic activism working against discourses of breast cancer as a cosmetic disease and threat to femininity (Lorde, 1980/2020). Through this militant act, though, Sarah and Leslie have attracted stigmatizing responses which have further politicized their performances through connecting their hereditary cancer experiences, and related preventive measures, to socio-political issues, such as gender and sexuality. In response, they enact the role *of defender*, pushing back on the misunderstanding and misconception surrounding their preventive choices.

These examples show how hereditary cancer content fits within what has been labeled as "serious tiktok": that is, when TikTok is used to communicate "socio-political affairs in engaging ways (. . .) while harnessing the platforms features, aesthetics and dialects to creatively unpack complex topics" (Ebbrecht-Hartmann & Divon, 2022). In the context of hereditary cancer, these politicized performances can be constructed in layered and complex ways drawing on multiple platform features. Sarah, for example, performs the defender through two overlaying modes: video text and the audio sound bite that she lip syncs (a practice already linked to political communication, see Ozduzen et al., 2024; Zeng & Abidin, 2021). This complexity, however, is not necessarily required, with Lesie performing her defender through engagement with one responsive feature: that of the comment reply and Jade relying solely on direct speech to play the role. These examples, though, have one thing in common: they are *dialogic*. By this, we mean that they all work to respond to, and engage in conversation with, their respective audiences.

The mentor

The third role we see being performed in hereditary cancer content is that of the mentor. Here, users construct a supportive, empathetic self that gives recommendations, instructions, and encouragement to their audience. To illustrate, we return to the example of Leslie (seen in Figure 6). After Leslie directly addresses the user who left her the comment, she turns her attention to her own community (the flatties) saying:

> I know this person is not going to care about what I have to say. So this is for anyone else, and for you flatties who have had this kind of thing happen. There are a million different ways to look like a woman. Don't be this guy's idea of what a woman is supposed to look like, be your idea of what you want to look like. (Leslie)

Figure 7. Jake.

Jake also performs as a mentor (Figure 7). Jake addresses his audience in his car before heading to a chemo round (he has Lynch Syndrome, but has been battling cancer for 6+ years). He spends this video reflecting on his emotions about having cancer at Christmas time, before turning his attention directly to his followers, saying:

> Don't isolate, don't feel like you're alone in these feelings, don't feel ashamed of them. Which is something I'm trying to work on. We're all trying our best to go through it, just remember you're not alone. Life with cancer sucks and it's hard. But we take it one day at a time and i'm here for you. (Jake)

Sarah (seen in Figure 8, the same creator featured in Figure 5) also performs as the mentor in her BRCA content. Her video shows her sitting on the floor stretching with a slow, contemplative instrumental playing as audio throughout. Video text then appears on the screen, one sentence at a time: "To anyone going through it right now/I know how heavy it can all feel/ but take a deep breath/ it'll all be ok."

Figure 8. Sarah.

These examples perform a self that takes leadership, or holds a hierarchical position, over their audience. They do this through their language, with all creators drawing on imperative verbs, for example, don't be this guys idea of what a woman is supposed to look like (Leslie), don't isolate, don't feel like you're alone in these feelings, don't feel ashamed (Jake), and take a deep breath (Sarah), to instruct and advise their followers on what to do or how to feel. This commanding language, though, is balanced out by a performance of empathy in the way creators express similarity of feeling. Sarah does this through her expression of knowing "how heavy it can all feel" (Sarah) and Jake's use of "we" and "we're" to represent togetherness bringing him back down to the same level of his audience. Through these performances, creators are drawing on the didactic cancer narrative noted by Hawkins (1999): a narrative "motivated by the explicit wish to help others" that involves a "blend of practical information with a personal account of the illness" (p. 128). The mentor role, though, is less about helping through teaching or educating and more about helping through emotional encouragement, support, and connection.

Discussion and conclusion

This article has explored how identities are constructed in hereditary cancer content on TikTok; specifically, we show how identity is performed through playing *roles*, that is, the playing of a part or character in order to create a self "that an individual wants to project to the world" (Kivisto & Pittman, 2011, p. 330). Through the performance of these roles, certain qualities, or dispositions of character, are emphasized as important in experiences of hereditary cancer. The celebrator illuminates qualities of strength, bravery, and resilience while creating a space for both normative and non-normative presentations of self and femininity to emerge in complex entanglement.

Through the defender, TikTokers perform a politicized self, standing up for their choices as well as to stigma and misconception, linking their experiences to socio-political issues. The mentor role allows for content creators to perform a self who can lead and be looked up to while simultaneously being an empathetic figure to relate.

Scholars have argued that how sociality unfolds on TikTok is different from other social media platforms and that concepts such as the "algorithmized self" may be more applicable than older frameworks like the "networked self" (Bhandari & Bimo, 2022). Our analysis, though, has shown how interpersonal and networked elements of identity still emerge. Creators on TikTok engage in an array of communicative and technological features to directly converse and connect with their audiences. Performing the celebrator role involves the visual and textual display of social ties and relationships (a defining feature of older social media socialites, see Papacharissi, 2011). Through the defender role, we see creators responding to, and engaging in conversation with comments from their respective audiences through direct comment replies as well as through performing interactive skits. Through the mentor role, creators work to directly connect to, and speak with, their community using inclusive language, and direct instructions to coach individuals through challenges associated with hereditary cancer and cancer treatment. These roles show how performances of self remain networked (in the sense of performing to networks through networks (see Quinn & Papacharissi, 2018)) but also how these performances can indeed remain *connected.* This is particularly relevant to mentor and defender performances where real links are established (through comment replies) or performed (through empathetic, supportive selves). Ultimately, the roles identified within our analysis show how, as Baym (2015) once argued, "identity is always social" and that, despite the changing platform logics that drive TikTok identity is still "made, displayed and reshaped in interaction" (p. 119).

With this in mind, although we find value in the notion of the algorithmized self (Bhandari & Bimo, 2022), we counter the argument that this form of self-making somehow displaces older frameworks. This distinction is important as often, as scholars of new media technologies, we become preoccupied with questions of newness and innovation and neglect the idea that the new can exist alongside the old. These arguments are historically made in relation to new modes and mediums of communication (Bolter & Grusin, 2000; Shapin, 2007); however, we argue that they can also be applied to understandings of sociality and identity online. In making this case, we are not dismissing arguments made about intra-action between algorithms and user, in fact, our methodological approach does not

allow us to do so. What we are arguing, though, is that, while making these arguments, we should not dismiss the relevance and existence of interpersonal interaction and associated concepts. Due to this, we contend that identity work happens in numerous spaces of social media. This includes the "intra-connection" space that encapsulates the relationship between user and algorithms (as highlighted by Bhandari & Bimo, 2022). However, it also includes the interpersonal space where identity is *still* performed in dialogic, networked, and connected ways. As Papacharissi and Easton (2014) argued that "old and new modalities" can exist in a "perpetual, dialectical shift" (p. 180), we argue that so can forms of sociality and identity performance.

In the interest of being nuanced around labeling social media phenomena as new, we thought it appropriate to highlight how our analysis has shown familiar cancer narratives such as pink ribbon culture (Sulik, 2014) as well as didactic (Hawkins, 1999) and transient (Boer & Slatman, 2014) narratives as present within identity performances in hereditary cancer content on TikTok. Building on findings from Vicari and Ditchfield (2024), we note that one difference in hereditary cancer content on TikTok, compared to that of other social media, is the presence of more non-normative representations of conditions, for example, flattie content. However, what this article has illuminated are the different forms of identity performance involved in these non-normative representations. It is indeed celebrated (through *the celebrator*) and used as a springboard for support (through *the mentor*), but it also has to be defended (through *the defender*). This utilizes the militant metaphor often associated with cancer (Sontag, 1978/1991) in an alternative way: the battle here is not with the disease but instead with misunderstanding social media audiences, also raising questions on the extent to which TikTok is a supportive, safe space for hereditary cancer creators.

This article has contributed to knowledge on experiences of social media and hereditary cancer by shedding light on the kinds of identity performance that become most visible through ways of sociality shaped by powerful multimodal and algorithmic platforms such as TikTok. Going back to Rose's (2023, p. 47) conceptualization of the intersecting sites at which meaning is made, this contribution sits at the site of meanings created within the social media content itself. Due to our methodological approach, we can, however, speak to the fact that the identity roles of defender, mentor, and celebrator appear within the most visible, and arguably most popular, content connected to #BRCA and #lynchsyndrome, thus also revealing something about the kinds of identity performance that are circulated, engaged with, and broadcast by the platform. Ultimately, this provides unprecedented insight into the type of narratives users are exposed to when seeking information and support in relation to a hereditary cancer diagnosis on TikTok.

Yet, what we still know little about is the decision-making processes that occur at the *site of the production* of hereditary cancer social media content. To explore this, future research must engage with the creators behind the screen. With this in mind, we agree with Wellman et al.'s (2023) call for research to continue taking "the platform itself into greater consideration" when examining hereditary cancer content on social media (p. 2448) but extend this to call for research that asks hereditary cancer content creators how their experiences intersect with their understandings of a platform's features and structures.

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Ethical approval and informed consent statement

The research has received ethics approval from the University of Sheffield. Due to the public nature of the posts collected and analyzed, informed consent was not obtained from content creators. However, we have taken steps to pseudonymize the content shared within this article.

Author contributions

H.D: Conceptualization (lead); data curation (lead); methodology (equal); formal analysis (lead); writing—original draft preparation (lead); writing—review and editing (equal). S.V: Conceptualization (supporting); funding acquisition (lead); data curation (supporting); methodology (equal); formal analysis (support); writing—review and editing (equal).

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Data availability statement

The IDS of the posts analysed in this article are available (on request) on ORDA (The University of Sheffield's Data Repository).

Note

1. "The storyteller," while frequent, showed weaker elements of sociality so we decided not to include it in the discussion.

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Author biographies

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Stefania Vicari (PhD) is a Senior Lecturer in Digital Sociology at the University of Sheffield (UK) and a research lead at Sheffield Cancer Research. Her work, funded by the British Academy (2012), the Wellcome Trust (2013, 2016), the Economic and Social Research Council (2018), and the Leverhulme Trust (2022), investigates digital participatory cultures and lived experiences of health and illness.

Appendix

ATTRIBUTE CODES (technical)	
1. Modes of communication present (a video could communicate via more than one mode)	• Captions- text that appears underneath videos • Hashtags- use # and often appear after the caption of a video • Written video text- written text appearing in the video content • Audio- sound present in the video (types of sound broken down in a separate code)
2. Type of Audio (a video can draw upon more than one type of audio)	• Soundtrack – backing music, usually a song or instrumentals • Audio meme – voice based. Not the voice of the person in the video but a replicable sound that can be re-used by others on the platform • Direct speech - creator is directly addressing/speaking to the audience through audio • Voiceover – this could be 1) the creators voice playing over video content or 2) an automated voiceover playing over video content • Sound from other media- e.g. sound comes from the use of a media clip
3. Technological features (specific technological effects or features that creators can include within their videos through the TikTok platform. A video can include multiple features)	• Comment reply- where a specific TikTok comment is featured/pictured within the actual video content • Green screen- a video that has a 'faux' background • Duet- a video posted side-by-side with a video from another creator on TikTok • Stitches – a video that combines another video on TikTok with one of the creator • Transitions- a video that connects two or more video clips • Split screen- a video where the screen is split into two or more sections • Filters- appearance altering effect (not always clear if creator has used, but sometimes it is made explicit)
ATTRIBUTE CODES (visual)	
4. Video genre (style/genre of TikTok video. Videos that share similar characteristics. A video can fit more than one type)	• Dance – video that involves replicating a dance trend • Lip sync – video that involves the creator lip syncing over a soundtrack or audio meme • Make over – video involves a physical transition or change of appearance • Talking to audience- video that involves a creator talking directly to their audience either via voiceover, direct speech or video text. • Get ready with me (GRWM)- a video that involves the creator talking through an element of the 'getting ready' routine. Often clothes, hair, makeup orientated • Montage- a collection of images/videos from different times and locations presented together in one video/ slideshow. • Documentary- video documents some aspect of reality/real life/daily life • Challenge- creator is engaging with an existing social media/TikTok'challenge'. Challenge videos 'challenge' creators to engage in a particular action or task • Role play- playing out a scene or interaction • Media footage- using media footage e.g. clips from news, youtube videos (not their own)
5. Setting (where is the video set?)	• Home/studio setting – set in what appears to be the previvors home and or studio • Medical – scenes of previvors/creators in medical settings e.g. doctor's office/hospital beds • Nature – scenes of previvors/creators in nature (beach, forest) • Urban - scenes involve city or urban environments, can also include car

(Continued)

Appendix. (Continued)

ATTRIBUTE CODES (visual)	
6. Props (objects used/featured within the video content)	• Clothing/cosmetics- includes/features clothing, makeup, hair, wigs, jewellery. items of clothing are interacted with/ made a focus/send a particular message (not just present) • Nudity- parts of the body that are 'usually' covered (e.g. a woman's chest) are on display. Often involves displaying wounds/scars • Medical equipment - bandages, machines, wires • media equipment - microphones • food
7. Who (is in the video (visually or via sound) e.g. does the video feature the 'previvor' or is it a family member?)	• previvor/s • cancer survivor/s • family members or friends of previvor/cancer survivor • health professional • other/unknown e.g. video is a media clip of groups of people
DESCRIPTIVE CODES (topical)	
8. Hereditary cancer topics (what element of hereditary cancer are creators talking about/referring to?)	• Mastectomy w/o reconstruction (content oriented around this particular preventative measure) • Surgery/treatment (reason for, prep for, actual process, recovery from, this can include content about chemo) • Common criticisms/misunderstandings related to condition/preventative measures adopted • Community – content refers to the idea of there being a community surrounding their condition. coded as yes if using hashtags like 'flatties' as the discourse is that this a 'group' who have taken the same preventative options • Challenges of condition- physical, emotional, mental • The biology/science behind gene mutation - defining gene mutations • Stats - how common conditions are/risks involved • Fertility related/choices/journeys • Testing and diagnosis - testing for genetic mutations, content about diagnoses journeys
9. Social topics (does the content link to any societal issues or topics outside of hereditary cancer?)	• Sexuality – refers to creators sexual preferences/orientation/desirability • The body/appearance – directly refers to the way a woman looks. Not just the display of nudity, but the topic/ messaging behind the content is ABOUT the body. This could refer to the physical attractiveness of a woman (this could be the creator themselves), or what a woman should/should not be doing with their body. Could also include justifications of what previvors have done with their bodies. • Family/relationships – refers to the relationship the previvor/creator has e.g. with partner, family members, friends
ANNOTATION	
Stance/position towards topics discussed	A space to note down any thoughts/reflections on the kind of discursive work or behaviour that a previvor/creator was doing in the video. Examples could be working to defend or challenge, working to support or working to admire.
Identity/type of performance	A space to note down any thoughts/reflections on the kind of identity/performance that a creator is putting forward in the video.