

#strokesurvivor on Instagram Conjunctive experiences of adapting to disability

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Abstract

This study investigates practices of sharing the experience of stroke on Instagram through use of the hashtag #strokesurvivor. The hashtag brings together people from different cultural backgrounds and professions and those who experience different kinds of healthcare and varying degrees of physical or cognitive impairment. Through a digital ethnography of #strokesurvivor, the conjunctive experiences and communicative practices of the community are reconstructed. Instagram enables specific forms of sociality and sharing, like long-term visual storytelling and influencer dynamics. Adapting to a transformed body and identity is perceived and practiced as a conjunctive experience and a struggle. A strong orientation towards a “normal life” is a recurring theme. Mourning and perseverance are put forward as two modes of coping with and adapting to a transforming body and self.

Keywords

Instagram, health, illness, stroke, community, self-help

Introduction

There are over 12.2 million strokes¹ experienced each year. Globally, one in four people over the age of 25 will have a stroke in their lifetime. The often-traumatic experience of having a stroke is shared by a diverse group of people in terms of age, gender, origin, and profession. 63% of all strokes happen to people younger than 70, and 16% of all strokes occur in people 15–49 years of age (Feigin et al., 2022). A stroke can have a variety of mental or physical consequences, the most common being “impaired speech, restricted physical abilities, weakness or paralysis of limbs on one side of the body, difficulty gripping or holding things, and a slowed ability to communicate” (Better Health Channel, 2015).

On Instagram, the hashtag #strokesurvivor is regularly used by those who identify as such; more than 336,200 posts (as of August 2022) are labeled with it. The thematic framing suggested by the term “stroke survivor” is revealing, as stroke is not a neutral label like #depression or #ivfcommunity but foregrounds the shared sentiment of having survived something potentially fatal. Other related hashtags — like #strokerecovery, #hemorrhagicstroke, and #strokesurvivorsneverquit — refer to recovery or specific kinds of strokes; however, #strokesurvivor is the most popular stroke-related hashtag. A hashtag avoided by survivors is #strokevictim, which is commonly used when referring to those who have died of stroke. While the individual experience of stroke or brain injury can vary widely, the self-assigned term “stroke survivor” apparently still works best as the common term for a globally dispersed group of Instagram users.

As a stroke survivor and Instagram user myself, I was intrigued by the stories and dynamics that I encountered. As a media scholar, however, I was surprised to find a form of intimate connection and togetherness related to a health issue on a visual platform that has strongly been associated with superficial content and idealized, perfect images — at least until recently, as will be explained later. While individuals with various illnesses and their caregivers have used web-based media to connect and communicate since the early days of computer-mediated communication (Coulson et al., 2007; Maloney-Krichmar & Preece, 2005), the emergence of such communities on Instagram is a more recent phenomenon.

Two main research questions arose:

- *What kind of sociality is #strokesurvivor?*
- *What recurring narratives are constructed in participating accounts?*

The first question focuses on the collective and connective experience, asking how participants relate to each other and what role platform affordances play. Moreover, how might this ‘hashtag public’ on Instagram be different from other health-related communities in terms of shared experiences and communicative practices? The second question relates to individual/biographical accounts, with an emphasis on the role of the visual and stroke-specific narrative trajectories.

To answer these questions, I systematically investigated the hashtag through an online ethnography. In contrast to existing, often quantitative approaches to health issues on Instagram, this study provides a more fine-grained, differentiated perspective on these phenomena based on my long-term involvement and understanding of the field as an affected person.

To situate the results, existing research on networked social formations around health and illness, Instagram as a platform and fieldsite, and hashtags as connecting agents will be briefly introduced, followed by the methodological approach and the presentation of the findings.

Social connection: From online forums to social media

The possibility of connecting with others online is especially relevant for those suffering rare diseases or those belonging to a small group of affected people who have a hard time finding a community offline or organized support for their “unpopular” illness. This is the case for those using the hashtag #strokesurvivor on Instagram. As the 16% of “young” stroke survivors were already using the platform before they had a stroke, they naturally seek connection regarding stroke on Instagram. Moreover, the COVID-19 pandemic made the need for physically distanced, safe spaces of communication around health and illness especially critical.

In her study *Participatory Cultures of Health and Illness*, Vicari (2021) finds that mainstream social media like Facebook, Instagram, and YouTube grew in importance as spaces in which to share information and learn, construct, and narrate individual experiences about health and illness (p. 99). This growing importance also transformed practices of anonymity and pseudonymity (Hogan, 2013; van der Nagel & Frith, 2015). On Instagram, users can choose any username, but they often include at least their first names and places of residence in their bios. As the platform focuses on sharing photos, and most users also share photos showing themselves, pseudonymity can really only go so far. While anonymity/pseudonymity seems to encourage intimate self-disclosure, for example, in the context of mental health (Andalibi et al, 2017, p. 1497; McCosker, 2018, p. 4755), it does not seem relevant in the #strokesurvivor community, as will be elaborated below.

As social media becomes a route to connection for people with illnesses who go online for information, support, advocacy, or comparative experiences, so-called “illness subcultures” emerge (Conrad et al., 2016, p. 23). However, concrete practices vary greatly and depend on the affordances of the platform or digital environment, on the one hand (boyd, 2011; Bucher & Helmond, 2017), and on the specific illness or health issue and the level of social stigma attached to it, its treatment, its trajectory, and its “(medical) popularity”, on the other.

Considering this, it stands to reason that the emerging forms of sociality may vary as well. While “networked publics” (boyd, 2011) may function as an umbrella term for all of them, as would concepts of post-traditional *Vergemeinschaftung* (German for communit-

ization) (Hitzler et al., 2009), more recent ideas adopt a different perspective on belonging and togetherness: While the term used by Conrad et al. (2016), “illness subculture,” merely describes the social connection around a specific disease within a broader online culture, Döveling, Harju, and Sommer (2018, p. 2) base their work on online grief and propose the concept of “discursively constructed digital affect culture,” focusing on the aspect of “emotional alignment that gives rise to feelings of belonging.” Similarly, “affective publics” (Papacharissi, 2014, 2016) and “networked affect” (Paasonen et al., 2015) highlight the somatic intensity of material, embodied experience that may mobilize agency and action (see also Hanna & Gough, 2017; Roen et al., 2021). While these concepts focus on somatic and affective aspects and seem enlightening regarding health and illness communities, the similarity of lived experiences and emerging connective practices were particularly relevant in #strokesurvivor. I therefore propose the idea of “conjunctive experience” (Mannheim, 1922/1997) for a better conceptual understanding of this form of sociality in the findings section.

To summarize, in analyzing health and illness communities on social media it is crucial to consider the specific experience and nature of the health issue at hand and how it relates to the particular platform culture and affordances, and what form of sociality is constituted in and through communicative practices.

Instagram: Platform culture and affordances

Instagram is currently one of the most popular social media platforms, with 1 billion active users and 500 million daily active users (Statista, 2022). Instagram was first developed as a photo-sharing app in 2010 and quickly became an important platform for the advertising industry. It was bought by Facebook (now Meta) in 2012. The majority of its users are 18 to 34 years old (Statista, 2022). Instagram allows the sharing of photos and videos in the account feed, in stories (which are online for 24 hours), and in direct messages. A common perception is that the aestheticization of everyday life on social media has been promoted by Instagram (Leaver et al., 2020); however, the omnipresence of seemingly perfect bodies and lives has also been problematized (Wells et al., 2021). In recent years, and especially during the pandemic, the platform transformed from a primarily visual, glossy, and polished space into a more politicized, activist, and educational one, as a broad range of communities and hashtag publics asserted themselves on the platform (Al-Rawi, 2021; Childs, 2022; Drüeke et al., 2022).

It is therefore interesting to investigate #strokesurvivor as a health-related form of sociality within the specific visual and emotive media ecology of this platform. In contrast to the text-heavy media spaces sometimes used by illness subcultures, Instagram’s default communicative mode is visual microblogging, in the sense of sharing cumulative self-presentations (Walker-Rettberg, 2014, p. 35). While mailing lists, chat groups, and forums are built on thematic structures and the exchange of lengthy written information and experiences, and the sharing of links and sources (Hanna & Gough, 2017; McCosker, 2018;

Roen et al., 2021), Instagram, due to its particular interface and platform culture, does not accommodate these practices.

The accounts participating in #strokesurvivor primarily post stories of personal experiences or emotional reflections, which might be proof that the diary format of Instagram is particularly well-suited “for supporting disclosure of vulnerable, negative, or stigmatized experiences and emotions, enabling recording the trajectory of one’s experience” (Andalibi et al., 2017, p. 1497). The platform offers possibilities for interacting with this content through liking and commenting on posts in the publicly visible feed or stories, via direct messages, and by tagging other users or reposting their content. However, all content is always situated within an individual account.

Therefore, hashtags are important tools to connect posts and label content thematically. They can be defined as techno-social assemblages, or as “pathways to an open and non-predefined set of communicative encounters and architectures, a cross-roads between form and matter, medium and message entangled” (Rambukkana, 2015, p. 4). #strokesurvivor does not only label the content of pictures within the ecology of this specific platform (Highfield & Leaver, 2015), but it opens up potential for the emergence of a networked public, a community for those who share the experience of stroke. Young stroke survivor Madison shared with me that she is “in a community now because of the hashtagging, because people found my hashtag helpful and they found me [...] and that’s how I find people too.”

Instagram’s chronological and algorithmic structure makes the most recently posted and popular content more visible. The platform does not function as a thematic repository that can be searched, like forums or Facebook groups. While users can scroll through accounts and hashtags, it can seem quite coincidental if and when content pops up in their feeds and stories (Bucher, 2017). This transient, ephemeral mode of communication, however, seems suitable for the constantly updated narratives of recovery after stroke, as is elaborated in more detail later.

Moreover, visual modes of communication offer specific affordances: With the rise of smartphone photography around 2007, user-generated content took a visual turn (Pink, 2011; Van House, 2011), culminating in the practice of selfies (Tiidenberg, 2018). In multi-modal environments, visual cues are more salient than verbal ones; they capture attention and increase emotional involvement (M. Müller & Geise, 2015; Scheufele, 2003). Collective knowledge, visual repertoires, and perceptive conventions structure the way we show and see the world around us (Baxandall, 1972; Sturken & Cartwright, 2005) and therefore also how we imagine healthy, abled bodies. With omnipresent, networked cameras, we can generate an archive of pictures of our own bodies (Walker-Rettberg, 2014). Those pictures allow us to perceive the expressiveness of our corporeal appearance from an assumed external perspective and therefore control the body as a social-symbolic medium (Goffman, 1959; M. R. Müller, 2011, p. 95). This also has a huge impact on digital communication around health and illness: Apart from therapeutic and medical documentation of

bodily transformations, practices of self-surveillance and curated self-presentations are especially relevant in social media contexts (Gómez-Cruz & Lehmuskallio, 2016; Schreiber, 2017, 2020). The role of images will therefore also be investigated in this ethnography.

Studying health and illness on Instagram

While the social dynamics and affective intricacies of text-based health communities — mainly online forums — have been researched in quite some detail (Andreassen, 2017; McCosker, 2018; Roen et al., 2021), health on Instagram has so far been not been heavily investigated. When it has, it has mainly been via quantitative content analyses of large data sets of public posts, captions, and comments, and identifying the themes and tonalities of posts and the respective response and support practices: Andalibi et al. (2017), for example, investigated Instagram posts about #depression and found that posts were a place to express negative feelings and experiences, often through personal stories. That personal stories trigger more reactions and support was also found in a study on another health-related hashtag, #melanomasucks (Cho et al., 2018, p. 9). Moreover, data suggests that Instagram may be “a place for legitimizing experiences rather than finding more pragmatic help [...] to seek support, find similar others, and disclose stigmatized experiences” (Andalibi et al., 2017, p. 1496ff). Similarly, a study on the #ivfcommunity on Instagram finds that the platform is used “to share experiences, express emotions, offer and receive support, and provide and receive treatment education” (Perone et al., 2021, p. 619).

While these previous studies focused on the role or relevance of Instagram for illness communities via quantitative analysis of posts, this study adds an in-depth ethnographic account of the long-term social dynamics of such a hashtag public, integrates the perspectives of the users themselves, and takes a closer look at visual sense-making throughout the accounts.

Methodological approach

Data collection and positionality

As already mentioned, this study offers an analysis of a specific hashtag public based on long-term and personal involvement. As a stroke survivor myself, I have been following the hashtag on Instagram for over a year since my own stroke; I started to systematically conduct a digital ethnography on the topic in late 2019. The data collection took place exclusively online and I was immersed in the field over a long period of time, mainly focusing on Instagram, but occasionally moving to other online spaces to follow participants' blogs, websites, or podcasts. My personal involvement proved to be a door opener during data collection, yet it was sometimes a challenge during data analysis, which I tackled through constant reflexivity and the discussion of interpretations in research workshops.² The fieldwork coincided with the first year of the COVID-19 pandemic and related lockdowns, which did not make a difference, as offline fieldwork was never planned.

Drawing on digital and social media ethnography (Hine, 2015; Pink et al., 2016), I focus on practices and the digital artifacts that are the results of these practices (Bräuchler & Postill, 2010), but also on the features and interfaces of the platform as they “configure the environment in a way that shapes the participants’ engagement” (boyd, 2011, p. 39). Rather than presupposing that #strokesurvivor is a community, I was interested in how users of the hashtag understand and construct forms of digital sociality around the hashtag through their routines, contributions, and interactions (Postill & Pink, 2012).

To gauge the field, the hundred most recent public posts marked with #strokesurvivor were documented at three points of time (October 2019, February 2020, July 2020), and a visual content analysis (Geise & Rössler, 2013) of these 300 posts was conducted. The largest number shows stroke survivors in private or mundane contexts, and half of the posts are portraits and selfies of the survivors by themselves. Overall, these contributions represent and celebrate a return to a “normal life”, often showing the stroke survivor being able to conduct activities as they could before the stroke. To explore these first impressions and the hashtag further, I collected qualitative data from October 2019 until the end of 2020, including field notes, screenshots, interviews, and posts.

Sampling strategy

Through long-term observation and interviews, 37 public accounts were identified as actively participating in the community through regular posting and commenting under the hashtag. About two-thirds of these accounts are stroke-specific, which means they were started specifically for stroke recovery documentation or advocacy, usually in addition to existing personal accounts. They often include the term “stroke” in their Instagram handles and are usually started around one year after the actual incident. Most of the less-active users add the stroke aspect to their existing personal accounts. Among the 37 accounts, there are twenty-five female survivors and seven male survivors, two female caregivers, and two organizations, as well as one occupational therapist. About half of these actively participating accounts are from the US; the rest are spread out globally, but users mainly come from English-speaking countries like Canada and Australia, and some European countries.

The intensity of engagement varies: About ten users are very active or could even be understood as professionalized contributors to the hashtag; they also use other media outlets like podcasts, books, or workshops. A larger group regularly posts and comments on content without strategic or activist intentions but with a focus on individual experiences and challenges. Those who just consume content but remain invisible are quite possibly the largest group, as stroke survivor Chris remarks:

It’s for the people out there who you’ll never speak to. They don’t have it in them to reach out to you, but there are so many of them out there that will see your stories and look and

say, wow, that person is doing it, I can do that too. So, they might not reach out to you, but you're reaching them. (Chris)

I approached ten contributors who were particularly active in terms of community building and personal storytelling and conducted interviews with eight of them. All participants gave informed consent regarding the use of their data. No institutional ethics approval has been obtained, as this is not obligatory or common in Austria. However, research followed the AOIR ethics guidelines (Franzke et al., 2020). All quotes from participants' posts are verbatim and pseudonymized and have not been corrected or changed.

Data analysis

Field notes and interviews were coded inductively with MaxQDA and interpreted following the principles of grounded theory (Clarke, 2003) and documentary method (Bohnsack, 2014), which conceptually fit the research questions. Selected posts of the interviewees and related comments have also been subject to close readings to investigate storylines and recovery narratives that are constructed, with specific attention to visual forms of sense-making.

The findings are presented in a gradual, "zooming in" way, starting with an analysis of the specific #strokesurvivor sociality and community practices that emerged in the ethnography and the interviews. The second findings section focuses on the phenomenon of "strokefluencers," who represent the middle ground between collective and individual experiences. Finally, based on close readings of posts, the typical storylines of stroke survivors are discussed.

Findings

"It's horrible, but I'm so thankful that we have this community": Conjunctive experience and ambivalent intimacy

Stroke survivors on Instagram share an existential, life-or-death experience and a transition phase based on a crisis: the sudden loss of mental and/or physical abilities at a relatively young age, loss of autonomy and independence, dependency on caregivers, and long-term recovery. Their close bond is built through their shared fate, which can be conceptualized as a "conjunctive experience," a basic element of Mannheim's sociology of knowledge (1922/1997). "Conjunctive knowledge" emerges from a lived, embodied experience that is shared with others, without necessarily having experienced it together but still sharing the existential implications and therefore connecting on a deep level. According to Kettler, Meja, and Stehr, "Such knowledge is inherently qualitative, judgmental, situational — and it belongs neither to the isolated individual nor to any universal human faculty. Conjunctive knowledge pertains to communities, constitutes communities, is borne by communities" (1980, p. 408).

Yet, the #strokesurvivor bond is built on a twist of fate that no one chose, so what emerges is an ambivalent kind of intimacy:

There's a certain amount of understanding that only we have and I love that, as crazy as it sucks that we're part of this community. It's horrible, but I'm so thankful that we have this community. (Chris)

This unique shared experience of stroke definitely “sucks” and is “horrible,” but also creates a strong connection and sense of trust and familiarity among those affected. The emerging intimacy is therefore always ambivalent and double-edged, as no one becomes part of #strokesurvivor by choice. But at the same time, finding fellow survivors who understand the struggle on a deep level is comforting, motivating, and makes other differences less important:

I think that this little corner of the world, this like, place, it's really- It's really a good place of love. 'Cause like, I have followers have really different political views and in the US right now we're so split. And it's really kind of a scary time, but when we come together on this topic, it is only love, only support, only, only acceptance. And, uhm, and challenge, but in like, in a really healthy way. (Amelia)

Amelia mentions “challenge” within a “place of love.” This could be an ambivalent experience, as watching others' progress or recovery while one is not getting better oneself might be burdensome. I can confirm from my own experience that this can be both motivating and frustrating. Still, users are united through having survived something that could have been fatal — in contrast to other illness subcultures, which might focus on avoiding death or identifying the right treatment.

#strokesurvivor also emphasizes the fact that the community might not be an illness subculture after all, but should maybe be understood as a recovery or disability subculture. For a more nuanced understanding of these socialities, the different temporalities of relevant conjunctive experiences should be taken into account: They might include a trauma in the past with consequences in the present (like a stroke), a fatal threat in the present (like cancer), or a hope for the future with treatments in the present (like #ivf-community). Stroke survivors are not trying to overcome an illness but are rather struggling with the extent and permanence of the consequences of a brain injury. Moreover, the sense of recovery, the hope, and the struggle to regain functions is also shared by at least some survivors, but without the realistic prospect of a complete recovery. In its suggestion of the profound transformation of everyday life and recalibration of self, #stroke-survivor can be likened to communities connecting over chronic illnesses like celiac disease (Conrad et al. 2016) or endometriosis (Melander 2019), but it has its own specific trajectory.

*Overcoming loneliness as a young survivor*³ was often named as the initial motivation to search for the #strokesurvivor hashtag on Instagram. Offline support facilities were

often experienced as being mainly designed for older people, and many survivors felt their relatives and friends could not empathize with their experiences: “I know the feeling of isolation where you feel that you’re all by yourself, even if you have people around you” (Chris).

Following fellow stroke survivors on Instagram creates a sense of familiarity, and the responses to shared content make survivors feel understood. They are finally “talking to people who understand — you know, who get it” (Lauren). This mutual connection is built on their *sharing of personal stories and firsthand lived experiences, which in turn creates an authentic and trusting environment.*

I think it's personal stories. I'm really into them, reading, and I try to connect with new people. I spend a lot of time commenting on other people's posts and support, uh- commenting supportive messages and telling them thumbs up if they've done some great work [...]. And people feel more normal and it creates a sense of security, I think, for many people that they are not alone in this and what they are experiencing is valid. (Sara)

Like, I really wanted it to be more relevant stuff that people can relate to and not so much, oh shit- Like, I don't want someone to look at me and go, oh, she's a stroke survivor. I want people looking at me like, oh my God, she did her hair. I know how she got her hair done. (Madison)

To summarize, the participants in #strokesurvivor are not gathered together by choice, but by fate. However, they foreground their conjunctive experiences and find solace in shared struggles. While it is hard to find other young stroke survivors offline, a globally dispersed group of them comes together under a hashtag on Instagram. Intimacy and belonging are built relationally as they receive understanding and offer it to others through their images and stories. However, some of these relations become hierarchical as more experienced survivors come forward as “strokefluencers.”

“Why don't you tell the world?": Being a “strokefluencer”

In self-help communities, people with a problem tend to help other people with the same problem, which is often also beneficial for those giving the help.⁴ In the stroke-survivor community, the more “experienced” or less affected survivors also *feel responsible or even “called to” support others.*

I'm a walking miracle, so I kind of feel like I came back to help our community, I do. So I have a passion to reach out and connect with as many survivors as I can and help them on their journeys, which in turn is gonna help other people on their journeys, and I know that sounds really grandiose, but I really feel like we can change the world that way. (Chris)

In previous research, health influencers were found to emerge in different ways. On Twitter, for example, they act as curators of (scientific) information and sources. Users whose messages are frequently retweeted and whose handles are mentioned often become

gatekeepers of the public for an issue (Vicari, 2021, p. 29). In anonymous mental health groups, on the other hand, users become health influencers in that they are peer mentors and role models through their intensive engagement, non-professional expertise, and authority (McCosker, 2018, p. 4750).

#strokesurvivor influencers are somewhat similar to mental health mentors, but mainly seem to be niche micro-celebrities. First and foremost, “strokefluencers” are experts at storytelling and sharing their own experiences. They usually do not share scientific or medical information but focus on how they overcame challenges. They also benefit from their helping role. Their own posts show up regularly in the #strokesurvivor feed, they often comment on others’ stroke posts, and they are regularly mentioned and tagged. Sometimes, connections made with other users can lead to peer mentoring, but this usually takes place “behind the scenes,” through direct messages or other private conversations beyond Instagram. NGOs like @differentstrokesuk also try to become more popular and visible by inviting users to share their personal stories on their account.

To elaborate and illustrate these dynamics, the Instagram accounts of two strokefluencers will now be introduced and analyzed: those of Neo (@the_road_to_recov-

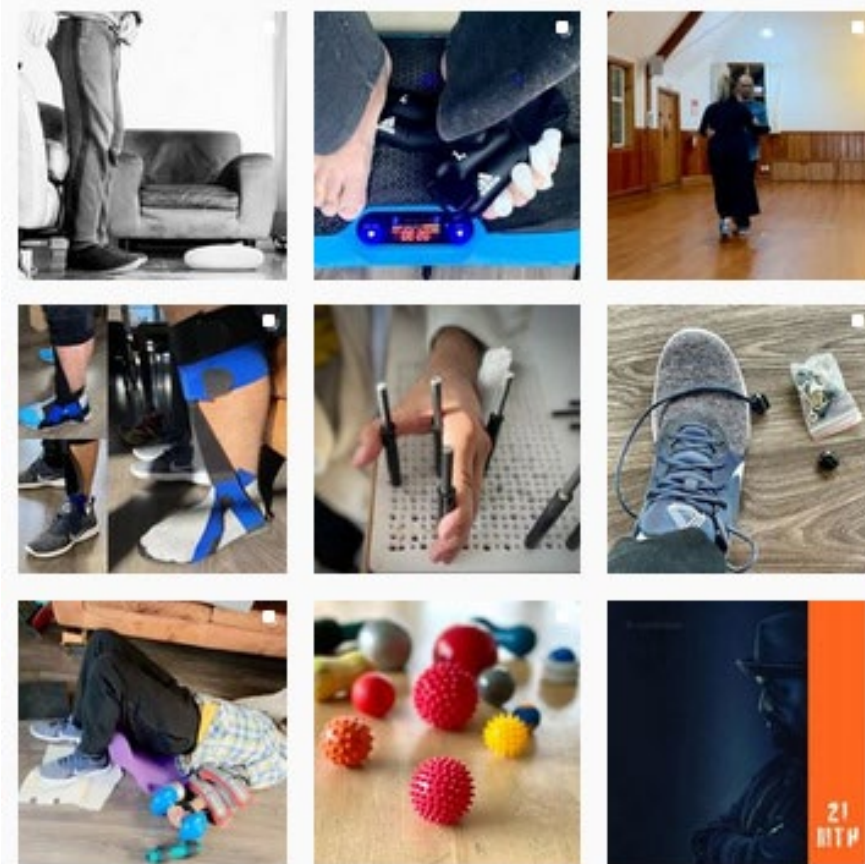


Figure 1: Screenshot of Neo’s account (@the_road_to_recovery_2020)

ery_2020) and Madison (@diffstrokes4difffolks_). Both explicitly chose not to have their accounts anonymized.

A first glance, Neo’s feed (see Figure 1) shows that he posts a lot about therapeutic tools, gadgets, and splints. He started his account after his stroke, and the account name also includes a reference to the term “recovery.” In his Instagram bio, he states the date of his stroke and describes himself as a stroke survivor, but he also mentions other roles like father and designer. His motto is “share to inspire,” which he discussed in the interview:

you end up giving advice, which obviously, I’m not a therapist [laughs], I’m just going through this, trying to figure things out. But people are looking for answers and it’s- Just like me and, you know, you’re looking for stuff and hopefully can pass something on. And, uhm, and it might be useful to someone. (Neo)

Neo started the account with pictures from the hospital. His feed is very homogenous and resembles a fitness account in that it mainly features pictures and videos of exercises, tools, and training sessions. He regularly posts videos of himself walking in the same place to document his progress over time. Selfies and inspirational quotes are rather rare on his



Figure 2: Screenshot of Madison’s account (@diffstrokes4difffolks_)

feed, but a recurring series of posts in dark colors show a portrait of him and the number of months that have passed since his stroke (see lower right corner, Figure 1). He uses the captions for this series to reflect upon his emotional state. The length of the captions varies.

Madison's account gives a very different impression (see Figure 2). She shares content from her everyday life, text posts, portraits, and videos of herself talking into the camera. She had her stroke at the age of 24, which she mentions in her bio along with her place of residence and her private interests, which include dogs and donuts. She also shares a link for a local fundraising campaign, indicating her activist engagement in the community. Overall, her account resembles a diary or blog. It features people close to her and personal content about her wedding and the pandemic, but also "throwback pictures" to her life before the stroke. However, she also shares rather dramatic pictures of the time she spent in the hospital. A large element of her account is about how she copes in her everyday life as a newly disabled woman. In contrast to Neo's provision of functional-physical content, she focuses on reporting on her achievements and struggles with mundane activities like doing her lashes or going shopping in a very open and humorous way. Accessibility issues, like the lack of dedicated parking spots or insurmountable stairs, are another important topic on her account. More recently, she has been producing comedic TikTok videos, mainly making fun of herself or how others react to her disability.

Both accounts have been created alongside the users' pre-existing accounts to focus on stroke-survivor content. Neo and Madison initially wanted to share their experiences to keep their families and friends up to date, but as strangers started following them and as they became more active in the community, their accounts became more "public." However, both keep their personal accounts separate and relatively "stroke-free." While Neo does not want to continuously confront his friends with the topic, Madison specifically aims to detach her activist community engagement from her personal life. She even posts the same content on both accounts but frames it differently. For example, on her personal account she shows how good her make-up looks, but on her stroke account she explains how she managed to make it look that good using just one hand.

Users like Neo and Madison are micro-influencers and connecting nodes in this networked public, which also entails specific expectations regarding their exposed position. They produce content that is perceived as helpful by other stroke survivors and is shared widely. They are consulted for advice in the comments sections but also through private messages; answering those generates time-consuming unpaid labor.

However, the ways in which they offer support vary, which is related to the general narrative the accounts have established. Madison, for example, likes to offer support, "not like in a bossy way but in a more like, it's okay, like, comforting, more nurturing and not so much, okay, you gotta do this, you gotta do this, you gotta do this, right?" way. Neo prefers to focus on concrete advice,

or like hey I have a question, how do you suggest I do this, and, like, so now I really just use it to stay connected with that community and just try and be a helping hand as much as I possibly can. (Neo)

But he feels it is important to set emotional boundaries: “I’m sympathetic to, you know, people’s struggles and journey, but I got my own struggle”. Olivia, who hosts another popular account, feels similarly, saying, “I’m really not here to make people feel... good all the time?” While the emergence of influencers in this niche on Instagram is probably not surprising, the different styles of content creation are entangled with different modes of adapting and coping.

***“It looks like I’m always succeeding”:* Adapting to a new sense of body and self**

Adapting to a new sense of body and self is the overarching, recurring theme in individual accounts and collective communication under #strokesurvivor. But how do participants adapt? What are the “cultural storylines” or “shared beliefs” (Melander, 2019, p. 72) within this transformative process? Charmaz (2018) finds three major stages of adapting to impairment. After 1) experiencing an altered body and impairment, people experience a loss of body-self unity. They 2) reassess who they are and redefine their future identity accordingly. Then they 3) finally surrender and open themselves up to experiencing their illness, thus transforming the self and reuniting with the body. Through biographical disruption, the “erstwhile taken-for-granted world of everyday life becomes a burden of conscious and deliberate action” (Bury, 1982, p. 176), with those affected often withdrawing from social relationships (Bury, 1982). However, online relationships with fellow survivors seem to compensate for the lack of understanding in offline relationships, as has been elaborated above. Moreover, becoming a “wounded storyteller” can become a way of recovering one’s voice, because “as wounded, people may be cared for, but as storytellers, they care for others” (Frank, 2013, p. xx).

The practice of storytelling as an *easily accessible form of empowerment* and the *development of a narrative over time* is enabled by the *microblogging structure* of Instagram. #strokesurvivor accounts usually start with the stroke itself and are exclusively dedicated to the topic. Before-and-after posts are also a recurring genre in the community, enabling a diary-like tracking of recovery progress. Lauren asserts, “I love doing the comparative videos because it reminds me of what something used to look like and what it looks right now and then it’s easier for me to see progress”.

A recurring (visual) topic is the *orientation towards a “normal” life*. Doing mundane things like going shopping or walking the dog for the first time after a stroke is often celebrated with a post. Survivors hope to gain back physical and cognitive functions to be more self-reliant. Therefore, finding and providing already tested practical advice is another frequent topic; this advice includes therapeutical tips but also everyday life hacks, like how to open a jar using only one hand.

Visual media prove to be effective for expressing difficult emotions (Andalibi et al., 2017, p. 1486) and emphasizing the embodied, somatic aspects of health and illness. However, not all disabilities or illnesses are visible, and pictures can also be used to create the impression of “being normal” or to hold onto a previous, healthy self-image. While written exchanges might enable “the development of collective reflexivity” (Akrich, 2010) in the stroke survivor community, *the specific visual quality of shared photos and videos contributes to the mediation of embodied practices and emotional expressions*. Moreover, pictures *allow for affective co-presence* (Licoppe, 2004; Villi & Stocchetti, 2011) rather than cognitive reflexivity: “because you can hear what they sound like, you can see their mannerisms when they speak, you know, you kind of get a feel for who these people are” (Chris). What is more, *photos are treated as proof and authentication of lived experiences*, because their truth value is rarely doubted (Hand, 2012, p. 80). Finally, the fact that pictures are easier to process makes them the preferred mode of communication in a community of recovering brain injury survivors: “I struggle reading long paragraphs and articles and Instagram is mainly pictures” (Sara).

Adapting to impairment is perceived as the hardest challenge in the context of strokes, as strokes disrupt the previous sense of body and self (Charmaz, 2018). Moreover, a stroke-specific challenge is accepting high prognostic insecurity regarding the actual extent of remaining impairments while keeping up hope, motivation, and efforts to further rehabilitate (Lucius-Hoene, 2008, p. 608). Within this challenging phase of transformation and adaptation, *mourning* and *perseverance* were identified in this investigation as two critical polarities of sense- and self-making in the #strokesurvivor community. Two



Figure 3: Screenshot of Madison’s post

posts illustrating these modes are discussed in more detail as examples for coping and adapting through visual and narrative media in the specific semi-public space of Instagram. However, these two modes represent two ends of a spectrum as they can also be combined in different ways or alternate throughout an account.

The picture shows Madison with messy hair, crying with her eyes pressed shut, holding her hand in front of her mouth, sitting in the corner of a room. It is a screenshot, most probably taken during a video chat on a camera phone. This mediated modality is marked by the black bar on the top that gives information about time, battery, and signal status, and the X button to close a window in the top left corner. Moreover, something has been crossed out with black, erratic lines, maybe white text giving information about the video chat partner. As the black lines are positioned directly above Madison’s crying face, they resemble a crown of thorns or a comic dark cloud. On both the iconic-visual and the mediated level, the picture shows expressive hiding. Madison shows a burst of emotions, but at the same time hides them as she closes her eyes, hides her mouth behind her hand, and turns her head away from the camera.

The expressive hiding is also reproduced in the lengthy caption for the picture, where Madison discusses whether it is legitimate to thematize and show negative emotions on this platform. She describes her struggles with expectations that she thinks others have; it is unclear if they are real or if they are actually expectations she has for herself: “I’m supposed to be the strong confident badass that survived two strokes.” She calls herself a “superhuman” who should not be sad or weak, but on this day, it was too much: “I feel



Figure 4: Screenshot of Neo’s post

like I'm not seen as a human anymore. I'm seen as a handicap." Madison's perception of the disabled body as "non-human" contradicts the image of the "survivor" or "superhuman" who escaped death and has already gained back important abilities. In the caption, she *explicitly mourns the loss of her old self*, which is quite unusual in the community, yet the comments for this post validate this experience of grief, with many replying that they have felt the same way.

The assumption or belief that functions can be regained is a prerequisite for the other *coping mode of perseverance*. Working on overcoming impairments is a recurring imperative in the stroke survivor community; however, the problem with brain injury is that it is very hard to predict or even roughly estimate how much function one can gain back, as stroke recovery is complex and non-linear (Grefkes & Fink, 2020).

In Figure 4, we see a mirror selfie of Neo in a frontal pose that is common in fitness or training contexts. His upper body is centered in the frame and part of his face is cut out. While the left side of his body is blurred, a black strap covering his right arm is in focus. The clear black lines of the strap contrast with the white and pastel background and the soft yellow t-shirt. While fitness selfies usually show naked upper bodies to demonstrate training success, Neo presents a therapy tool that improves the posture of his affected body. In the caption, he describes how his shoulder is already more active and how the strap helped him find the right angle. The mirrored self-portrait suggests a more distant, objectifying perspective than a classic selfie with the camera pointed directly at the body. Neo visually frames his body in a rather mechanical and fragmented, de-individualized manner and elaborates on the practical steps of using the tool and training to improve movements in the caption.

The two modes of adapting to impairment that have been introduced represent two ends of a spectrum: on one end, with the practice of mourning the loss of the familiar, healthy body (see Figure 3), grief and sadness are laid open and met with empathy and reassurance, and mourning is practiced collectively; and on the other end is a positive outlook and strong belief in recovery (see Figure 4).⁵

While displaying endurance is a recurring theme that is validated and praised by the community, practices of mourning are rather rare. Balancing mourning and perseverance, or more generally sharing negative and positive content, is a contested issue that users also reflected upon in the interviews. Sara and Lauren, for example, try to balance out the content in their accounts, but avoid being too negative:

I've had some feedback that I only show the pretty side, so I try to balance it out, because everything is not possible. It looks like I'm always succeeding in all my- all my work, but I'm really not. And it's a balance. But I, I, I- I decided early that I wouldn't have an account that was too negative. (Sara)

I'm not against sharing negativity and setbacks sometimes, like occasionally I post a story where I talk about things that didn't turn out the way I wanted, too. But we kind of use that as a motivation to get better out of it, you know. (Lauren)

Like Lauren, who uses setbacks as motivation, Olivia criticizes posts which just ruminate without looking to change that.

Like, it's okay to be sad, and (that)'s like, Well. Yeah! But it's not okay to ruminate. And I think that's what people are doing, when you're posting about being sad! And like, it- it should be like, 'Okay. I'm sad, but now what.' And I'm not seeing that 'Now what', I'm just seeing 'I'm sad!', 'I'm tired!', like that's fine, but you have to have the 'Now what'. (Olivia)

However, Lily, a caregiver, emphasizes the importance of showing the mental struggle alongside the achievements.

I think it's important to show the other side of stroke, which is what we also we're trying to do. Like all the mental health issues, uhm, days when you just don't wanna get out of bed, uhm, yeah, stuff like that. Which I think if you put too much of the achievements out there, they- people don't really see, I guess, the other side. (Lily)

Interestingly, both ends of the spectrum — mourning and perseverance — hang on to the healthy, able body: It is either mourned as something that has been lost or it serves as a future goal for recovery. However, the current status quo — the sick or disabled body — is usually not (yet) fully acknowledged as a part of survivors' identities. In Charmaz's (2018, p. 672) terms, this would mean not (yet) actively surrendering⁶ to the sick body, not being willing to flow with it, and not integrating it into a sense of self.

It seems that on an individual, biographical level, Instagram and the #strokesurvivor practices reconstructed above are especially relevant and helpful in a critical phase of transition and orientation: the journey towards acceptance of a transformed sense of body and self. Storytelling empowers.

On a societal level, the common link between modes of both mourning and perseverance is that disability is stigmatized and usually not (yet) accepted as part of a transformed identity, which can be understood as internalized ableism. While "ableism is attitudes, actions, and circumstances that devalue people because they are disabled or perceived as having a disability" (Ladau, 2021, p. 70), internalized ableism refers to the fact that disabled people might also take on these societal assumptions "against" themselves. This deeply personal, and at the same time social, struggle is only shared implicitly in #strokesurvivor accounts.

Limitations

This online ethnographic study explored a specific niche sociality — survivors of stroke on Instagram — from a media and communications perspective. The hashtag is predomi-

nantly used by a young, white, and Western demographic. While some findings might be applicable to other health issues, platforms, and demographics, a broader comparative study with other hashtag publics on Instagram or stroke survivors on other platforms could reveal how findings like the existence of emerging health influencers, ambivalent intimacy, or practices of public storytelling might be typical or specific to platform cultures or disease patterns. Another limitation is that the perspective of the silent lurkers of #strokesurvivor is only represented by me, the ethnographer herself. Future research could try to investigate their user experience in more detail instead of focusing on vocal participants.

Conclusion

In terms of sociality, #strokesurvivor on Instagram was found to be a globally dispersed community constituted by the shared experience of a life-changing event and the struggle with its consequences. This specific hashtag public can therefore be understood as a conjunctive space of experience, in the sense put forward by Mannheim (1922/1997). The hashtag brings together a diverse group of people on Instagram who nevertheless share the experience of a fundamental disruption of the sense of body and self.

Compared to older forms of illness subcultures, like more formalized discussion groups or lists, hashtag publics on Instagram proved to be rather loose, temporary, and algorithmically influenced collections of posts and accounts that one can subscribe to but also unfollow at any time. How the community presents itself is therefore highly individualized and curated in different ways in the feeds and media practices of participating users. The different temporal structures of illness communities and their growing or shrinking relevance in specific phases could be another interesting area for future research.

The integration of a disabled body as part of one's identity is not only a biographical but a societal challenge that involves practices of mourning and perseverance. As has been elaborated, this strong orientation towards a focus on the loss or reacquisition of the healthy body shows that participants experience internalized ableism and wrestle with the acceptance of physical and cognitive disabilities. On Instagram, stroke survivors mainly seek self-assurance and role models throughout this process, or even become role models themselves.

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Notes

- 1 “A stroke [...] happens when blood flow to the brain is blocked. This prevents the brain from getting oxygen and nutrients from the blood. Without oxygen and nutrients, brain cells begin to die within minutes. Sudden bleeding in the brain can also cause a stroke if it damages brain cells. A stroke is a medical emergency. A stroke can cause lasting brain damage, long-term disability, or even death.” (NHLBI, 2022)
- 2 Research workshops are an essential tool of quality assurance in the German-speaking tradition of qualitative, interpretive methods. Through discussing analyses and interpretations, they are developed and clarified further (Allert et al., 2014).
- 3 The recurring themes identified in the analysis are emphasized in italics.
- 4 This phenomenon has already been well-known for a long time as the helper therapy principle (Riessman, 1965).
- 5 However, this mode of perseverance and positivity can become toxic when it does not allow doubts or weakness. “Toxic positivity” refers to an overly optimistic perspective that ignores valid reasons to be pessimistic. This mindset is embedded in a “contemporary cult of happiness” (Wright, 2014, p. 795), but also in neoliberal ideas of healthism (Lupton, 2018).
- 6 “Ill people define their experience as newly authentic when they realize that having an ill body is part of them and they allow themselves to experience it” (Charmaz, 2018, p. 672).