Mobilizing stories of illness in digital contexts:

a critical approach to narrative, voice and visibility

Abstract

Illness stories have been celebrated as a resource for giving patients voice from the active position of the wounded storyteller (Frank 1997). The proliferating research on illness stories, however, has often reproduced a reductionist approach to narrative as a window to subjective views and experience based on a largely underdeveloped and essentialized notion of voice. Critics of the over-celebration of narrative have called for caution towards the use of personal stories (Atkinson 2009, Woods 2011), pointing to the need to situate constructions of the narrative self in their social, cultural, and political contexts (Schiff 2006: 21).

In this article, I discuss a new type of illness stories that has emerged in digital contexts as entrepreneurial narratives (Stage 2017) characterized by the connective mobilization of illness for producing various forms of economic and social value. Using small stories (Georgakopoulou 2015) and affective positioning (Giaxoglou 2021) as my analytic lens, I examine the specific case of story-design, curation and sharing of the COVID-19 diagnosis of actor Idris Elba in March 2020. As I will argue, the illness experience is mobilized in small stories online as a resource for authenticating the self in line with templetized modes of sharing, blurring the lines between the personal voice and the public visibility of storytelling. The article contributes to the critical study of the mobilization of stories across domains and its limits (Mäkelä 2018, Meretoja 2018, Meretoja and Davis 2018).
1. Introduction

In the context of Western, patient-centered medical practice, telling stories of illness has been advocated as a valuable resource for giving voice to patients. Communicating what it feels to be ill, arguably, empowers patients in medical encounters and can reduce institutional asymmetries between doctors and patients. It also allows patients to navigate and negotiate the challenges and identity changes they experience during their illness journey from the active position of the wounded storyteller (Frank 1997).

In recognition of these communicational and affective benefits, illness narratives have been extensively used as pedagogical resources for the training of medical students and physicians’ professional development practice. Specifically, in what is known as narrative medicine, physicians are encouraged to develop their narrative competence, i.e. their ability to acknowledge, absorb, interpret and act on the stories and plights of others (Charon 2001). The therapeutic functions of illness narratives have also prompted a burgeoning industry of illness memoirs as an auto/biographical genre in their own right written by patients or their caretakers (Vickers 2016). This genre rose to prominence particularly during the AIDS pandemic of the 1980s (Jurecic 2012). Illness narratives now form a well-established object of cross-disciplinary study for scholars concerned with the enhancement of healthcare practice or with questions of narrative, experientiality and identity.

The profusion of talking and writing about illness has, however, tended to privilege a vision of storytelling as inherently ethical and beneficial to both tellers and their audiences. Since the early 2000s, critiques to what had seemingly turned into an over-celebration of storytelling were put forward along with calls for caution vis-à-vis the use of personal stories as straightforward reflections of experience (Atkinson 1997, Atkinson and Delamont 2006, Atkinson 2009, Woods 2011). Instead, the importance of situating constructions of the narrative self in their social, cultural, and political contexts was noted (Schiff 2006). And yet, such critiques did not make it into the mainstream of narrative research or practice. More recently, Meretoja (2018) and Meretoja and Davis (2018) have (re)turned attention to the critique of narrative, arguing for the importance of avoiding idealizations of storytelling in favor of recognizing, instead, the ethical potential as well as the risks of different storytelling practices. As Fernandes (2017) has shown, for instance, the curation of stories of poverty and mistreatment in different parts of the world as heartfelt accounts end up detracting attention
from structural orders of inequality and undermine the confrontational dynamics of social movements.

In the current age which is characterized by a *storytelling boom*, stories - especially stories of personal experience - are being instrumentalized by individuals, but also by businesses and institutions across various spheres of everyday life, resulting in internally contradictory ethics and rhetorics of storytelling (Mäkelä et al. 2021). Attention to the empowering or disempowering uses of storytelling is acutely relevant in a digital age, where ‘stories’ are being mobilized as a communicative practice, and even as a feature on social media platforms, such as Snapchat, Facebook and Instagram (Georgakopoulou 2020). This is an era of intense (social) mediatization of social interaction as a series of *moments for sharing* (John 2017), whereby practices of design, curation and uptake of stories are subject to *social media logic*. Social media logic refers to the norms, strategies, mechanisms, and economies that characterize the dynamics of social media infrastructures, namely *programmability*, *popularity*, *connectivity* and which mediate users’ practices, technological platforms and economic structures (van Dijck and Poell 2013).

In this article, I provide an empirically-grounded discussion of the mobilization of illness stories in digital contexts exploring *practices of story design, curation and uptake in relation to narrative voice and mediatized visibility*. I use the term *mediatized visibility* to refer to the attention that some stories attract in online contexts on account of their appeal to social media logic. As I will argue, this type of visibility differs in a number of respects to the kind of recognition that can be gained through the use of stories for voicing personal experience.

I start with a brief overview of recurrent findings in the long-standing literature on illness narratives and pinpoint issues relating to emerging modes of telling the illness story on social media that are worthy of critical attention. I then move on to discuss a specific case of sharing a story of COVID-19 in the context of the coronavirus global pandemic in 2020. The contagious disease was first identified in Wuhan, China in December 2019, and a public health emergency of international concern was issued by the World Health Organization on January 30, 2020 before the disease, labeled COVID-19, was officially declared as a pandemic on March 22, 2020.

Based on the discussion of a COVID-19 story shared on Twitter by British actor Idris Elba and re-shared in the media, mainly in the US and the UK, I argue that small stories of illness
online are associated with the growing commoditization of the ‘wound’ and the mobilization of the illness experience as a resource for authenticating the self in highly conventionalized ways. This article contributes to the critical study of the mobilization of stories across domains and its limits (Mäkelä 2018, Meretoja 2018, Meretoja and Davis 2018) and the furnishing of critical approaches to storytelling, voice and visibility.

2. Illness as narrative

The study of stories documenting the experience of illness occupies, by now, an established place in narrative inquiry research. This line of research is a qualitatively-oriented approach in social research concerned with life experiences, people’s identities and social change where narratives – often elicited in the context of interviews – are used as a methodological tool with a range of real-world and political applications (Squire et al. 2014). The interest in illness stories has its roots in the so-called ‘narrative turn’ in the social sciences, which recognized narrative as “one of the most powerful forms for expressing suffering and experiences” (Frank 1997: 51). In addition, this interest arose in the context of a general reaction against medical dominance (Bury 2001) and in the midst of calls for more patient-centered approaches to medicine within which the importance of supporting physicians to develop their narrative competence was acknowledged (narrative medicine, Charon 2001). As a result of these calls, more systematic and sustained intersections among medicine, literature and the arts, and humanities were sought and are nowadays represented in the interdisciplinary subfield of medical humanities (Hurwitz et al. 2004).

The privileging of the patient’s life story created a space for bringing to the fore different kinds of patients’ experiences. Patients’ life stories were viewed as a way of supporting and empowering patients during the subjection of their bodies to medical treatments and rituals (Kleinman 1988). Illness stories are, in this sense, key resources for giving voice to those who find they have no voice as their social identities change while their bodies undergo treatment. More recent work has been drawing attention to patients’ ‘bodies’ as a source of narrativity as well as to the importance of the story listeners’ bodies in shaping narrative interaction (Hydén 2011). Less analytical attention has been paid, however, to the specific links of illness storytelling and voice, given that the positive and beneficial aspects of this relationship seem to have been largely taken for granted.

The notion of voice is intertwined with the notion of telling rights, i.e. the entitlement to tell a story on account of having taken part in an event or having first-hand information about it. Yet,
as De Fina and Georgakopoulou note (2011), the relationship between ownership rights and performance rights is a complex one, in that the former doesn’t necessarily guarantee the latter. This means that in some cases of asymmetrical participant relationships, it can be the most powerful speaker who has the right to perform the story, irrespective of the story’s ownership. Questions of narrative form as well as ownership and performance rights to a story are thus important in any critical investigation of the ‘voice’ afforded to tellers in different contexts, especially when stories get told in ‘new’ contexts, for example social media contexts.

A focus on narrative in the domain of illness opens up the academic exploration of narrative from a number of vantage points, including the way narrative is socially and culturally constructed; how narrative is embodied and expressed in addition to how it is represented from a biomedical point of view; and last but not least, how it relates to the sufferer’s meaning-making practices and world-constructions (Hydén 1997). As Shapiro (2011) acknowledges, however, a patient’s story is rarely just a story. It is, instead, the conscious and unconscious representation and performance of intricate personal motives and implicit narrative influences, i.e. cultural narrative models that affect the ways meaning making around illness, not explicitly fleshed out in textual form (Meretoja 2018). Such implicit narrative influences become evident in the plot types that have been found to guide the crafting of such narratives in specific social and cultural formations - at least in Western world contexts, where the bulk of this research has been conducted. According to Frank (1997: 101), these plot types include: the restitution narrative, which focuses on the conclusion of illness, the ultimate victory over illness, an individual’s reintegration into society and return to the normalcy of everyday life; the chaos narrative, an anti-narrative that highlights the interruptions caused by illness; and the quest narrative, which focuses on the temporal enactment of the illness experience and an individual’s transformation over time. For Bury (2001), there are three main types of plot types: contingent narratives, which focus on the details about the disease, its causes and its implications for everyday life; moral narratives, that address questions of illness and social identity; and core narratives, which explore deeper layers of meaning related to the experience of suffering and illness.

Despite the recognition of the links of such narrative formats to social and cultural conditions, the study of narrative form in the narrative inquiry and social science research has been mainly based on the analysis of monologic, elicited narratives, privileging one particular type of narrative, namely the life story or big stories. This type of story involves the telling of past experience viewed at a distance from the vantage point of the teller’s here-and-now. In the case
of the representation of the illness experience, this type of storytelling invites reflection on the biographical disruption brought about by the illness. As a result of this focus, a wide gamut of stories that appear less coherent and hence, less amenable to analysis are left out of this line of inquiry.

In applied linguistics - and more specifically in the subfield of health communication - there have been calls for the critical re-evaluation of existing narrative approaches to health (Harvey and Kotyeko 2013). This critical re-evaluation also needs to take stock of recent research on digital narrativity, affect and identity, if it is to address aspects of the reconfiguration of the personal and the public and its implications for theorizations of storytelling and voice, particularly in the case of illness narratives. A brief overview of relevant research developments is provided below as the main frame for the present discussion.

3. Illness as sharing

In an age of social media, personal experience is arguably being reconfigured as sharing, in the sense that it is being constituted, understood, and constructed in and through particular practices of broadcasting - and curating - significant moments with networked audiences. As Nicholas John (2017: 5) notes, sharing is now a metaphor we live by – it involves the entextualization of self, that is the construction of the self through text, written, spoken and/or visual means (e.g. messages, videos, images) with a focus not only on trivial moments, but also on life-changing events and disruptions, including illness, dying, death and mourning.

Early practices of documenting the contingent experience of illness emerged in blogs, as these were for some time a preferred mode for disclosing intimate stories, given their consideration as safe and empowering spaces. Linguistic research on narratives of illness on blogging platforms has shown the gender-specific patterns characterizing these practices and their use primarily for connecting to a community of users (Page 2011). More recently, connecting to networked communities has been taking place via video blogs, also known as vlogs, which afford users the possibility to video-document aspects of their lives. In the literature on illness narratives in digital media, observations about the benefits of digital illness stories as a resource for self-expression, peer-support (Liu et al. 2013) or the creation of support communities via the use of humor and sarcasm (Iannarino 2018) resonate with findings from earlier literature on the benefits of illness stories for patients.
More recent work has been pointing to ways in which such practices of storytelling are shaped by - and in turn shape - social media affordances and sharing norms. For example, in their study of narratives of Danish young people diagnosed with cancer, Stage et al. (2019) argue that younger users approach social media as vital media, which can help them address their different needs. Their sharing is based on their existing use of social media, meaning that users tend to align to a sense of an expectation to perform vital, i.e. positive or life-affirming, approaches to illness. The close links of these performances with the production of social and economic value and visibility has led to the description of these networked illness stories as entrepreneurial narratives (Stage 2017).

In my study of narrativity in the case of a vlogger diagnosed with terminal cancer (Giaxoglou 2021), I showed how a vlogger used small stories to relate details of her life with illness (e.g. medical updates) as well as aspects of her life despite illness (e.g. fashion), cumulatively making up the vlogger’s life story in ways that were more aligned to uses of social media as vital and entrepreneurial media and less to the typical plot types identified in the literature on illness narratives. In terms of temporality, the mode of storying in vlogging involved a mix of temporal foci on the vlogger’s here-and-now, the (recent) past and in some cases also, the future. In sum, the storying of illness online aligns to the typical features of digital storytelling, where storying is emergent, multi-semiotic and participatory (Georgakopoulou 2015) driven by - as much as driving - metrics of popularity and audience engagement (Georgakopoulou et al. 2020).

In the remainder of this article, I discuss an example of an online illness story in the context of the 2020 coronavirus pandemic, selected as a case that allowing the empirical investigation of the interplay of story design, social media affordances, narrative voice and visibility. I focus, more specifically, on the Twitter story of Idris Elba (full name: Idrissa Akuna Elba), an English actor, DJ (aka DJ Big Driis) and musician, known for his role as DCI John Luther in the BBC One series “Luther” for which he won a Golden Globe award and as Nelson Mandela in the film “Mandela: Long Walk to Freedom” (2013), among many other appearances in series and films. Idris Elba was one of the first celebrities to broadcast a public announcement about his COVID-19 positive diagnosis, on the 16th of March 2020, shortly after Tom Hanks and his wife Rita Wilson, who made their announcement ten days before the disease was officially declared as a pandemic by the World Health Organization (WHO) on the 22nd of March 2020.
Although there are limits to the insights that the examination of a single story can yield, the present discussion aims to highlight key aspects of story making and sharing online grounded in attested practices.

4. **Telling the COVID-19 story online: the case of Idris Elba’s Twitter story**

Celebrity and public figures’ announcements about their positive diagnoses and follow-up updates on their health became commonplace during the early days of the spread of the coronavirus disease. These included announcements by (or on behalf of) political leaders, such as the UK’s Prime Minister at the time, Boris Johnson, and the then-US President, Donald Trump, both of whom arguably used their stories of falling ill with COVID-19 as rhetorical strategies for repositioning themselves vis-à-vis their voters as legitimate and heroic leaders. In addition, stories of COVID-19 as experienced by people around the world also became a regular feature of broadcasts and media reports in the form of contingent stories of patients under medical treatment supported by oxygen in hospital rooms, stories of grief told by bereaved relatives after an often short and challenging period of illness, and stories of hope recounted by recovered patients. Narratives of battles and metaphors of war tended to dominate the telling of the COVID-19 story in ways that promoted a certain kind of fighting spirit and, in the process, avoiding the complexity and particularity of the pandemic crisis (Meretoja 2020). There has also been an increasing number of stories of long COVID recounting the personal experience of symptoms persisting long after the disease and contributing to the medical recognition and support.

Stories of illness in the media during the period of coronavirus became closely related with political messaging about governments’ reactions, the medical search for a better understanding of the symptoms of the disease as well as public messaging about socially responsible behaviour in a context of increased public health risk. In this broader context, some celebrities and influencers saw it as their role to contribute to that public messaging by sharing their personal experience stories with the disease. Idris Elba was diagnosed with COVID-19 while in the US preparing to start shooting for a new film. Even though he had no symptoms, he got tested after finding out that a person he’d been in contact with had tested positive.
The table below summarizes the tweets relating to the story from the 16\textsuperscript{th} March to the 22\textsuperscript{nd} April 2020. They include a combination of tweets, photographs, videos and live broadcasts posted by the actor as updates on his health (1 & 5) or as responses to the reactions of his followers (2, 3, 4, 6).

**Table 1. Timeline of Idris Elba’s story on Twitter**

<table>
<thead>
<tr>
<th>No</th>
<th>Date</th>
<th>Modality</th>
<th>Content</th>
<th>Reactions</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>16 March 2020</td>
<td>Tweet &amp; Video</td>
<td>Breaking news of testing positive with coronavirus</td>
<td>286.9K retweets</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>81.6 retweets</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1.2M Likes</td>
</tr>
<tr>
<td>2</td>
<td>17 March 2020</td>
<td>Tweet</td>
<td>Announcement of going LIVE on Twitter</td>
<td>698 replies</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1.4K retweets</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>23.4K Likes</td>
</tr>
<tr>
<td>3</td>
<td>17 March 2020</td>
<td>Live on Twitter P. I</td>
<td>Response to followers’ comments and questions</td>
<td>480 replies</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(6:57 min)</td>
<td></td>
<td>1.6K retweets</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>7.4K Likes</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>481.7K Viewers</td>
</tr>
<tr>
<td>4</td>
<td>17 March 2020</td>
<td>Live on Twitter P. II</td>
<td>Response to followers’ comments and questions</td>
<td>557.8K Viewers</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(17:51 min)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>25 March 2020</td>
<td>Tweet</td>
<td>Update on health</td>
<td>1.9 replies</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>2K retweets</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>30.4K Likes</td>
</tr>
<tr>
<td>6</td>
<td>26 April 2020</td>
<td>Tweet</td>
<td>Response to backlash (relating to his talking about an annual lockdown)</td>
<td>351 replies</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1.2K retweets</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>17K Likes</td>
</tr>
</tbody>
</table>

Idris Elba’s updates via his Twitter account are approached here as moments of narrative stancetaking, which Georgakopoulou (2021) defines as follows:
A moment of position taking where a speaker more or less reflexively mobilizes more or less conventionalized communicative means to signal that the activity to follow, the activity underway or the activity that is indexed, alluded to, deferred, silenced is or can become a story. In doing so, he or she positions him/herself as a teller: somebody who is in a position to tell and assume a point of view on the telling and/or told.

In my discussion of this example, I draw on an understanding of (small) stories “as discourse engagements that engender specific social moments and integrally connect with what gets done on particular occasions and in particular settings” (Georgakopoulou 2007: 117). As I will argue, stories of illness online mobilize illness for increasing social and economic value and visibility in ways that end up reconfiguring the personal and the public as well as the degree of the teller’s control over their story. Such practices have important implications for the type of narrative voice and visibility afforded to tellers.

The analysis of the story draws on the concept of affective positioning, which is an analytic calibration of identity positioning (Bamberg and Georgakopoulou 2008) aimed at addressing dimensions of affect performance as the ground for identity construction. In digital contexts of sharing, social actors are not only faced with a range of identity dilemmas (Bamberg 2012), but they also have to navigate dilemmas which relate to the affective production and authentication of their experientiality, that is the investment of their telling with credibility and genuineness. These dilemmas include, for example, the ways in which storytellers affectively negotiate the degree of (a) uniqueness and representativeness of the shared personal experience, (b) the call for audience identification or distancing, and (c) the sharer’s display of emotional control or loss of control on recounted situations in line with existing templates for storying the self and sharing emotion in different social media platforms. I analyze affective positioning empirically at the three levels posited for the study of identity positioning, namely the taleworld, the storyrealm, and the teller with a focus on how a teller emplots degrees of affective proximity or distance from the storyworld, their audiences, and their own emotional self (Giaxoglou 2021). The small stories and affective positioning framework is apt for capturing aspects of entrepreneurial story design and personal storytelling in digital contexts.

More specifically, the analysis attends to small storying, the sites associated with the telling and the teller’s positioning at different levels and in relation to the above dilemmas. These foci can be articulated into the following questions:
(a) How is the actor small storying of his experience with COVID-19 affectively construct its uniqueness and representativeness? (*emploiment at the level of the taleworld*)

(b) How does the teller’s narrative stancetaking construct different kinds of audience identification or distance? (*story design at the level of the storyrealm*)

(c) How does the actor affectively position himself vis-à-vis COVID-19, his audience and his own self through his emotional negotiations of control? (*emploioment and positioning at the level of the teller*)

In what follows, I discuss Idris Elba’s COVID-19 *story design, narrative stancetaking activity, and affective positioning* in turn and discuss the limits of narrative voice afforded in this mode of digital storying.

4. Story design

The main part of Idris Elba’s COVID-19 story is summed up in two tweets: a post made up of a tweet along with an accompanying video shared on the 16th of March 2020 and a follow-up tweet posted on the 25th of March 2020. Additional posts as well as a two-part live video (see Table 1) are supplementary to that main story, picking up elements of the initial post in response to followers’ reactions and challenges. In this section I will focus on the two main story tweets.

The initial tweet from the 16th of March 2020 is laid out below in numbered lines for ease of cross-referencing in the discussion:

**Tweet – 16th March 2020**

1. This morning I tested positive for Covid19.
2. I feel ok, I have no symptoms so far
3. but have been isolated since I found out about my possible exposure to the virus.
4. Stay home people and be pragmatic.
5. I will keep you updated on how I’m doing (two black fist emojis)
6. No panic.

The tweet is a *breaking news story* of illness announcing the news of Idris Elba’s COVID-19 test outcome, focusing on the very recent event of the diagnosis (l.1 ‘this morning). This fifty-two-word post serves as the story’s *abstract*, i.e. the part of the story that summarizes the point of the story in Labovian terms (Labov 2013). In this case, the abstract also has an
interactional function, as it is being used as a meta-communicative device framing the video-story that forms the main body of the post. (I discussed this framing later on in this section.)

Initial diagnoses of illness commonly become the occasion for publicly sharing illness stories. Such diagnoses are critical moments that mark a change or disruption to one’s everyday life and plans (Stage et al. 2019). In the case of COVID-19, this initial diagnosis carries additional weight and increases its tellability, given the unknown and uncertain outcomes of the course of the illness in each person, especially in the early days of the pandemic. The uncertainty of what a positive diagnosis means motivates the actor’s reassuring update on his condition (l. 2 ‘I feel OK, I have no symptoms so far’). The actor then lists the actions he had to take following the positive test, such as going into quarantine (even before the test results were known to him), which form, here, the ground for validating the public health guidelines that the actor reiterates in an advisory tone directly addressing his followers (l. 4 ‘Stay home people and be pragmatic’).

An extended version of this story is given in the self-recorded video that accompanies the tweet (see Table 2 for the full transcript). The video was posted at 6:18pm on March 16, 2020, and it features Idris Elba at close-up and his wife Sabrina in the background, occasionally nodding. The video allows for a sense of more direct communication and connection with the networked followers as viewers.

The actor starts the video with a greeting to his followers (l. 1 ‘hey, what’s up guys’), a typical video vlog story-opening strategy that establishes the teller’s explicit orientation to a direct connection with his followers (see also Giaxoglou 2021). He then moves on to break the news of his positive test results (l. 2 ‘so look this morning I got some test results back for coronavirus and it came back positive’) and offers a brief, first-order negative evaluation of the implications of this news for him (l. 3 ‘yeah and it sucks’). The video highlights the affordances of video-storying for engaging the viewers through involvement devices (e.g. l.2 ‘so look’, l. 4 ‘listen’, l.6 ‘look), which call attention to the main points of the story. In addition, the possibility for viewers to watch the actor in real-time talking about his experience serves as a resource for lending credence to it as an ‘authentic’ and true account. (This doesn’t mean, of course, that this account is not subject to challenges for its truthfulness.) In the remainder of the video, Idris Elba assesses the different implications of the test’s outcomes through a series of evaluations, either focusing on his personal reaction to the results (l.3), his health condition (l. 4), or explanations about why he got tested (l.5),
generally maintaining an upbeat and calm tone in reaction to the news of his diagnosis. After having established his experiential angle, he moves on to relate the main point of the story, which is to alert the public to the real health risks of the disease (l.6), the importance of telling others (l.7) and of being transparent about this despite the potential stigma (l.8), and the importance of being united (l.9). He closes his story by reiterating that he’ll continue the updates and that both he and his wife are doing okay, (l. 10) and urges his followers to remain positive and calm (l.11).

Table 2. Idris Elba’ video story transcript and its narrative sections

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
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</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Hey, what’s up guys.</td>
</tr>
<tr>
<td>2.</td>
<td><strong>So look</strong> this morning I got some test results back for coronavirus and it came back positive.</td>
</tr>
<tr>
<td>3.</td>
<td>Yeah and it sucks.</td>
</tr>
<tr>
<td>4.</td>
<td><strong>Listen,</strong> I’m doing OK. Sabrina hasn’t been tested and she’s doing OK. I didn’t have any symptoms.</td>
</tr>
<tr>
<td>5.</td>
<td>I got tested because I realized I was exposed to someone who had also tested positive. I found out last Friday that they were tested positive, I quarantined myself and got a test immediately and got the results back today.</td>
</tr>
<tr>
<td>6.</td>
<td><strong>Look,</strong> this is serious, you know, now’s the time to really think about social distancing, washing your hands. Beyond that there are people out there who aren’t showing symptoms and that can easily spread it, OK. <strong>So</strong> now’s a real time to be really vigilant about washing your hands and keeping your distance, OK.</td>
</tr>
<tr>
<td>7.</td>
<td>We’ve told our families. They’re very supportive. We’ve told our colleagues.</td>
</tr>
</tbody>
</table>
8. And, you know, transparency is probably the best thing for this right now. If you’re feeling ill and you feel like you should be tested or you’ve been exposed, then do something about it. All right, it’s really important.

| Evaluation (point of the story) |

9. Look we live in a divided world right now, we can all feel it, it’s been bullshit but now’s the time for solidarity, now’s the time for thinking about each other. There was so many people whose lives have been affected. From those who have lost people that they love to people that don’t even have it have lost their livelihoods. This is real, all right.

| Evaluation (point of the story) |

10. I just wanted to share my news with you guys and I will keep you updated as how I’m doing but so far we’re feeling OK.

| Pre-closing |

11. All right, man, stay positive and don’t freak out.

| Closing |

The follow-up post to this initial announcement shared on the 25th March provides a short update on the couple’s health via just a tweet and not including a video.

**Tweet – 25th March**

1 Hoping everyone is coping with this $@@!!

2 Currently still quarantine.

3 Sab and I still feel ok so far with no changes.

4 Dr told us that after quarantine we will be immune for a certain time since our antibodies fought this.
5 At some point we’d like to go home to London. Bsafe.

This tweet also opens with an explicit orientation to the audience recognizing that the present moment is a difficult time for everyone. There’s not much new information to add to the illness story, but a reiteration of the couple’s ongoing quarantine condition and their unchanged health situation. The final part of the post looks ahead to the immunity after quarantine and their desire to return to London.

In summary, the breaking news story of COVID-19 communicated through a series of text-based and video posts, places little emphasis on the documentation of symptoms, given that the story deals with the immediate aftermath of the news of the positive COVID-19 test in the case of someone who hadn’t shown any symptoms. The actor’s observance of the requirements in line with public health guidelines forms the main ‘message’ of the update and the key point of the telling. The diagnosis of illness is used, here, as the necessary experiential ground for convincing people that COVID-19 can happen to anyone and that it needs to be taken seriously.

The lack of any reportable medical updates in this case of an asymptomatic patient makes this a story of (st)illness, whose sharing is framed as a story told for the sake of the audience, rather than that of the teller. The story is designed as part of the broader COVID-19 story-in-the-making. This is evident in the actor’s reworking of the initial NHS public health messaging “Stay Home, Protect the NHS, Save Lives” (see Giaxoglou 2020) in a more direct address to his followers and with a focus on their emotional wellbeing (16th March tweet, l. 4 ‘Stay home, be pragmatic, no panic’; Video, l.11 ‘All right man, stay positive and don’t freak out’).

The design of the story along an envisaged broader public impact was affirmed by the actor himself, when interviewed by Oprah Winfrey on the 22nd March where he stated that: “I think given the context of the video, which was telling the world what has happened to us, we weren’t thinking about that specifically” [my emphasis]. His story was designed as a story that would tell the world their experience with the disease and be offered as an exemplar story through which the actor and his wife are seen to be taking a clear and bold stance to what’s happening around them. Idris Elba can thus be understood to use this story to affirm his telling rights in the public story-in-the-making about COVID-19 and claim a role in influencing the public to be socially responsible and remain calm.
With respect to the way the uniqueness versus representativeness of experience is negotiated in this story, the emphasis is on establishing this personal experience as more broadly representative. However, this claim is challenged by part of the audience on account of the lack of test availability to the wider population. In addition, the uniqueness of his experience ends up requiring additional negotiating, given that he is asymptomatic. Finally, parts of the audience also challenge the veracity of his very claim to having tested positive with COVID-19 or express their disbelief in the realness of the disease altogether. The next section turns to the actor’s narrative stancetaking activity in relation to his negotiation of audience identification or distance.

5. Narrative stancetaking

Idris Elba’s COVID-19 story is embedded in his existing posting activity and presence on Twitter through which he constructs and maintains a relationship of proximity to his followers. The actor’s orientation to this relationship is highlighted in the closing of his posts where he commits to keep everyone updated on how things go (16th March tweet - 1.5 ‘I will keep you updated on how things are going’; Video, l. 11: “I just wanted to share my news with you guys and I will keep you updated as how I’m doing but so far we’re feeling OK”). His commitment announces the launch of his illness story as a series of updates to come for the sake of his concerned followers rather than in the interest of the teller, and thus builds interactivity at both the level of the story’s design and its curation.

In terms of tellership, although the story is told by one teller, it is designed and shared as an interactional story opened up for the validation and scrutiny of the audience. Idris Elba’s tweets are shared as narrative stancetaking acts through which he calls for the followers’ participation to the story. The response of his followers (16th March post - 286.9K retweets, 81.6 retweets, 1.2M Likes) attests to the popularity of the actor and the visibility that it entails for his stories.

Replies to the breaking news story included expressions of networked stances of support via tweets wishing the actor to get well (e.g. “wishing you a speedy recovery”) and showing the followers’ affective proximity to the actor and identification with his experience. Others used this opportunity of the actor’s disclosure to publicly express their commitment to him, for example, by declaring their will for ‘heroic sacrifice’ (e.g. “Take me instead @god”) or heroic action (e.g. “Alight, imma kill the virus with my bare hands”).

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The majority of reactions to the story, however, had to do with urgent questions about his symptoms and his wife’s health or questions about getting tested. This focus on testing gave rise to a backlash to the story relating to the availability of testing during a time when tests were not widely available, not even for key workers (see tweets 1-3).

1. “That’s good news. How did you get started? How are sick people not able to get testing but healthy people are?”
2. “I am sorry to hear about your positive result. However how did you get tested with no symptoms? NHS Staff can’t get tested even with symptoms! Please use your position to help us instead. Sign the petition and share on change.org.”
3. “While I admire you sir, my question continues to be: How does a famous person get a test and results in three days, while the rest of us are begging for resources?”

Parallel lines of backlash revolved around the apparent lack of social distancing from his wife on the video (see tweet 4), who hadn’t been tested yet (she tested positive a few days later) and a ‘joke’ about Idris Elba not being black, playing at rumors that black people don’t get covid19 (see tweet 5):

4. “But don’t you think you putting your wife at risk? Yoh I know the Corona virus exist but I just feel these celebrities are paid to raise awareness on this. Because how can you quarantine but yet you with your wife?”
5. “Always suspected you weren’t black” (16 March, 115 retweets, 51 quote tweets, 2,205 likes)

There were also users who saw this story as an opportunity to challenge the public alert around the pandemic or altogether deny the existence of coronavirus. Some users suggested that the actor and other celebrities were lying about getting COVID-19 and that they were getting paid to go public about their ‘fake’ diagnoses. There were even a couple of instances of users hijacking the timeline to promote conspiracy theories around COVID-19.

Such reactions illustrate followers’ affective distancing and dis-alignment from the story, and effectively redirect the focus of attention and challenge both the uniqueness and the representativeness of the story, despite its design as both a personal and an exemplary experience. The actor appears to have little control over how his followers read and react to his story; the uptake of the story would seem to matter over and above its interactive story design and curation. Sharing personal moments creates positions of vulnerability for the teller, even – and perhaps even more so – if that teller is a public figure, as people feel
entitled to respond and participate to the story often through acts of disalignment. Such reactions trigger additional response posts from the actor, in this case a live video in two parts and a number of posts or direct replies to individual users.

In the live video, Idris Elba repositions himself and adds details to the story to counter some of the reactions and to distance himself from those who circulate conspiracy theories. He also offers information and explanations in response to challenges to the sincerity of his account, the conditions around his testing, and the calculated risk decision he took with his wife Sabrina about social distancing.

The actor’s video response highlights the way stories online serve as moments of narrative stancetaking that instigate the development of the story in different directions. This kind of *poly-storying* (Georgakopoulou and Giaxoglou 2018) involves users who get to contribute more or less consciously to the development of the story along different directions by aligning or disaligning to parts of the telling that are most relevant to them or by offering new lines of story development.

As suggested by the above details, Idris Elba’s coronavirus story goes some way to mark a difference from ‘traditional’ illness stories, given that it is curated as an *interactive* story in the making, which gets shaped by the public’s reactions. Such reactions are not always within the control of the teller, given how parts of his story get picked out as objects of evaluation from followers in ways that Elba himself had not necessarily anticipated.

This poly-storying expands outside social media and in the media. In the case of Idris Elba, media headlines regularly reported on his updates applying a range of frames to their coverage, focusing, for example, on Idris Elba’s health, hinting at possible connections with other public figures, or reporting on the backlashes to his story (see Appendix). In the six months that this story was in the making, it developed from a breaking news story of a positive diagnosis to a recovery story of an asymptomatic patient from coronavirus and a reflection on its mental health impact on the actor. These diverse cross-storying practices point to the dynamic and distributed nature of this type of storytelling online, which although attributed to a single teller is, in fact, poly-storied.

6. **Affective positioning**

In this final section, I will discuss Idris Elba’s story in relation to the actor’s affective positioning, with special focus on his negotiation of emotional control versus loss of control.
Across his posts, Idris Elba’s affective positioning is represented as a balancing act between the challenges, risks and fears that the positive diagnosis raises for him - especially given that he’s asthmatic - and the need to align with expectations for remaining calm, positive and forward-looking. One way that Elba projects this reassuring affective stance is to move the focus away from himself marking a distance from the details of his affective negotiation with the implications of having tested positive with the virus and, instead, projecting affective needs to his followers, for example the need for them to remain calm (Live video: ‘I’m ok, if I’m ok, you’ll be ok, don’t panic’). In this way, the actor assumes control of his emotions and stages an emotionally brave ‘patient’ who can stand up as a role model for others.

The actor’s recurrent? move from his unique experience to an experience that is to be taken as an exemplar, and from his own feelings to feelings and behaviors assigned to the public, blurs the boundaries between the personal and the public. This blurring raises questions about the narrative voice that this story articulates: Is the story articulating the voice of Idris Elba as an ‘ordinary’ patient worried about his positive diagnosis and the way this experience is going to be like for him? Or is it a story representing the voice of other patients who have already tested positive with COVID-19 or are likely to test positive in the future but may not have a similar public forum to tell their stories ‘to the world”? Or lastly, is this the voice of a celebrity and public figure inscribing his experience into the public story in the making and claiming his right to gain visibility as a public health influencer?

These different types of narrative voice appear to be co-articulated in Idris Elba’s story of (st)illness, but ultimately the story is designed as a story of a public health influencer affording the actor his positioning as a socially responsible public figure who can make a change.

This kind of digital storytelling where illness is mobilized as a resource for increasing the sharer’s visibility and strengthening their influence, narrative voice becomes even more complicated: story ownership rights and story performance rights intersect with sharing rights. Although everyone in principle has a ‘right’ to share their story, the reach of the shared story is heavily dependent on the sharer’s popularity and the metrics associated with it. In other words, narrative voice (which relies on a story being heard and made visible) is displaced by structures of pre-visibility online and their associated pre-distribution of sharing and performance rights based on metrics of popularity and number of followers.
7. Conclusion

Stories of illness are becoming common in digital contexts drawing on existing digital narrative formats and social media multi-semiotic affordances. As the discussion above showed, in these contexts, illness is used as a resource for narrative stancetaking that leads to its poly-storying. In the case of COVID-19 storying, the case of Idris Elba’s story showed how illness is mobilized for connecting with others through the representation of experience as a unique personal experience that is designed and curated as an exemplary story promoting ‘appropriate’ forms of public behavior and affect. The story’s design and curation do not, however, guarantee the positive uptake of the story. Rather, its interactivity invites not only supportive reactions, but also challenges and backlashes that are beyond the teller’s control.

The focus on a celebrity’s story brought to the fore a shift in the motivation for sharing stories of illness. For Idris Elba, the sharing of his testing positive for COVID-19 served as a statement about the seriousness and realness of the disease that he felt an urgent need to share with the public in a bid to influence that public, rather than functioning as an attempt to document his own experience and connect with others over that experience. This change suggests a shift from the wounded storyteller to the persona of a health influencer storyteller in digital contexts. Health influencers tend to be public figures with a large following whose popularity ensures not only the visibility of their stories, but also allows them to draw attention to broader public issues.

The case discussed, here, is a specific case of an illness story that represents only a fraction of the uses of illness stories. The reason I chose it for analysis in this article was to draw attention to the increased importance of mediatized visibility over narrative voice especially in digital contexts, where popularity is often a condition for sharing a story that will be heard and/or viewed. Despite the recognition of the inequality revealed by the pandemic (IFS, 2020), for instance, stories from marginal groups remain difficult to find. This differential value of story sharing ‘rights’ highlights the limits of public illness storytelling and calls for some caution in over-celebrating uses of social media for drawing attention to diverse experiences. It is, thus, important to look closer to establish which stories get told, by whom, for whom, when, which stories get high levels of visibility and what kind of visibility this is.

To conclude, this article has called for the need to revisit and foreground a critical narrative approach grounded in the empirical investigation of different kinds of illness stories in a range of contexts in line with related endeavours of story-critical orientations in narrative
studies (Mäkelä 2018, Meretoja 2018, Meretoja and Davis 2018). By presenting this critical viewpoint in this article, my aim is not to de-authenticate patients’ illness stories, but rather to re-authenticate and re-value them in digital contexts, so that the voices of patients (and patient groups) reach wider audiences and connections. Looking ahead, it is going to be vital for critical narrative work to address more systematically issues of voice in relation to emerging modes of mediatized visibility with a view to call out those modes of visibility that contribute to the silencing or the further marginalization of everyday experiences of illness and inequalities.

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Mäkelä, Maria; Samuli Björninen; Laura Karttunen; Matias Nurminen; Juha Raipola; Tytti Rantanen 2021, “Dangers of Narrative: A Critical Approach to Narratives of Personal Experience in Contemporary Story Economy”, Narrative 29 (2): 139-159.

**APPENDIX**

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<td>16 March 2020</td>
<td>Huffington Post</td>
<td>Idris Elba Tests Positive for Coronavirus</td>
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<td>18 March 2020</td>
<td>NDTV</td>
<td>First Tom Hanks and now Idris Elba? Twitter has “Had it” with Coronavirus</td>
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<tr>
<td>23 March 2020</td>
<td>Huffington Post</td>
<td>Idris and Sabrina Elba, who both have COVID-19, explain why they didn’t stay apart</td>
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<td>31 March 2021</td>
<td>Huffington Post</td>
<td>Idris Elba reflects on ‘incredibly lucky’ COVID-19 recovery and portraying a black cowboy</td>
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<td>1 April 2020</td>
<td>Hindunistan news</td>
<td>Idris Elba says he no longer has Covid-19 symptoms: ‘I came through and you can too’</td>
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<td>14 July 2020</td>
<td>Sky news</td>
<td>Coronavirus: Idris Elba says illness had ‘traumatic’ effect on his mental state</td>
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<td>14 August 2020</td>
<td>NME</td>
<td>Idris Elba thought he was going to die from COVID-19 “It was really scary”</td>
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<td>National Post</td>
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<td>Huffington Post</td>
<td>Idris Elba Describes Traumatic Impact Coronavirus Diagnosis Had on His Mental Health</td>
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