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Original Manuscript

# Is it all about storytelling? Living and learning hereditary cancer on Twitter

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## Abstract

Storytelling has long been used as a theoretical framework for understanding how we share information and learn about health – and illness – online. But is it all about storytelling on social media platforms? To explore how and to what extent personal stories shape health content on these platforms, this article presents an analysis of tweets discussing the BRCA gene mutation – a hereditary cancer condition. Theoretically, the study advances a new conceptual framework to explore social media practices within issue-based and long-lived social media threads. Methodologically, it develops a platform-oriented discourse analytic approach. Findings show that non-narrative content is actually more common than storytelling in Twitter conversations about BRCA, with a number of patient advocates acting as gatekeepers of scientific information. Most BRCA storytelling is mediated and shared in third person, with those at the heart of these stories becoming exemplars within the BRCA ‘subculture’.

## Keywords

Community of practice, epistemic community, experiential knowledge, hereditary cancer, intertextuality, issue public, lay expertise, patient advocacy, storytelling, Twitter

## Introduction

Social media platforms thrive on multiplying ways for people to connect via seeking, producing and sharing content. Health is a sector, among others, subject to ‘platformization’ (Helmond, 2015), namely to the norms and values embedded in platforms’ design to enhance connectivity. While acquiring value for both platforms and – public and private

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– health services (Van Dijck et al., 2018: 97–116), health content produced and shared on and across social media is also increasingly relevant for ordinary users and invaluable for patient communities who rely on these platforms to access, share and process information that is scarcely available offline (e.g. rare disease patient groups; Vicari and Cappai, 2016).

In opening up new routes for connecting around health topics, the availability of social media platforms has turned illness into a visible experience, with the public emergence of ‘illness subcultures’ (Conrad et al., 2016), that is, communities whose members directly or indirectly experience similar health conditions. This public turn has developed alongside three key dynamics: the emergence of online structures of peer support among individuals with the same or a similar health condition (Myrick et al., 2016; Tanis, 2008); the development of digital advocacy (Vicari, 2017; Trevisan, 2016) and self-advocacy (Trevisan, 2017) around health-related collective identities; and the impact of social media usage on the traditional doctor–patient relationship (Cohen and Raymond, 2011).

But how is meaning constructed online within these illness subcultures? For the past 20 years, storytelling, namely the act of sharing personal stories, has been studied as central to the understanding of how, why and with what effects people share information about health online (see, for instance, Hardey, 2002; Orgad, 2005). But can the storytelling paradigm fully explain these dynamics in the contemporary social media ecology?

By analysing tweets focused on the BRCA gene mutation – a hereditary cancer condition – this article investigates how and to what extent Twitter users rely on storytelling to share information about health and illness. Overall, the article advances a threefold contribution. Theoretically, by linking traditional and digital media research on ‘issue publics’ (Bruns and Burgess, 2011; Converse, 1964), ‘communities of practice’ (Gilbert, 2016; Lave and Wenger, 1991) and ‘epistemic communities’ (Akrich, 2010; Haas, 1992), it provides a conceptual framework to investigate knowledge construction on social media. Methodologically, it develops a platform-oriented discourse analytic framework to unpack how experience and expertise are communicated or built on social media platforms. Empirically, it shows that in long-lasting Twitter threads focusing on health storytelling plays a less central role than that discussed in previous digital research. The platform environment influences the way experience and expertise are communicated and received, with some patient advocates becoming exemplars within their illness subculture and others turning into gatekeepers of scientific expertise.

## **Health, storytelling and experiential knowledge**

It was not digital media that put storytelling at the centre of individuals’ conversations about health and illness. After Bury’s (1982) sociological interpretation of illness as a ‘biographical disruption’, growing research – by both sociologists and medical professionals – has pointed to the relevance of ‘illness narratives’ (Hydén, 1997) in coping with the life disruptions brought by disease. According to this comprehensive body of work, the telling of stories helps patients come to terms with their condition, redefine their social relations and reaffirm their sense of self (Bury, 2001).

Digital storytelling has been investigated as typical of online health-focused conversations since the early 2000s, when scholars started to draw attention to the way people share stories of health, illness and caring on the Internet in general (Hardey, 2002) or on online social spaces like blogs (Orgad, 2005), or multiuser environments (Bers, 2009) in particular. In her pivotal work on online breast cancer blogs, Orgad (2005) described storytelling as the act of creating ‘a framework that would capture [...] multiple and scattered events. [...] An attempt to produce a self-story that helps its teller and her listeners to make sense of her *experience*’ (p. 43, emphasis added).

Akrich (2010) took this research one step further in the direction of understanding the role of online health conversations – in her case in mailing lists – in the construction of health knowledge. Drawing upon literature on situated learning, Akrich’s argument develops from the concept of ‘community of practice’ (CoP), namely one that focuses on ‘colocated or distributed’ groups (Wenger et al., 2002: 25) whose ‘participants share understandings concerning what they are doing and what that means in their lives and for their communities’ (Lave and Wenger, 1991: 98). According to Akrich, individuals joining health-focused mailing lists form ‘communities of experience’, that is, CoPs specifically defined by their members’ (1) interactions around their experience – in this case, of health and illness – and (2) willingness to share the said experience with others.

In the course of these interactions, individual experiential information – that is disorganised fragments of personal experience – turns into experiential *knowledge*, namely organic and reflective accounts of health and illness, that often combine with medical data. Experiential knowledge is clearly distinguished from expert (or professional) knowledge as, contrary to the latter, its access is *not* ‘limited to those who have met the requirements of specialised education and formal training in a discipline and who possess appropriate credentials’ (Borkman, 1976: 447) (e.g. medical doctors). In other words, while expert knowledge is grounded in specialist education, experiential knowledge is based on personal experience.

According to Akrich, experiential knowledge exchanges can ultimately lead to the emergence of ‘epistemic communities’, that is, communities sharing argumentative resources – based on the combination of (patients’) experiential knowledge and (medical) expert knowledge – that are more likely to influence health policing than those based on experiential information alone (also see Haas, 1992: 3). In the author’s words, there is a ‘tipping point between communities of experience and epistemic communities, that is, the point where the learning achieved within the lists, the accumulated facts, the experiential and built-up knowledge *could* become a form of political action’ (Akrich, 2010: online, emphasis added). The political action Akrich refers to consists of advocacy and activism for patients’ rights to health services, information and research. In practice, epistemic communities can lead to the formation of patient and carer associations or groups mobilising for patient communities.

In line with Akrich’s (2010) work, Bellander and Landqvist (2018) have shown that patients’ and carers’ health blogs and forum discussions also lead to the emergence of epistemic dynamics. In particular, the authors identify epistemic dynamics in the way traditional expert knowledge is absorbed, confronted and used by those traditionally defined as ‘lay’ people (e.g. patients, patients’ families), namely individuals with no medical training who draw ‘on their experiences of illness and recovery to recommend

health treatments' (Hardey, 2002: 41). To be clear, the epistemic surfacing in Akrich's (2010) and even more in Bellander and Landqvist's (2018) work does not translate into direct political action but rather into discursive practices that, by incorporating the experiential and the expert, show heightened potential to develop into health campaigning and/or advocacy.

While this epistemic perspective is also emerging in research focused on contemporary specialised health social media – often labelled 'digital health platforms' (Lupton, 2014) or 'experience exchange platforms' (Van Dijck et al., 2018), investigations of mainstream platforms (e.g. Facebook, Twitter) seem to be primarily reverting to the storytelling paradigm. In their work on visual and multimodal social media platforms (i.e. Flickr and Tumblr), for instance, Gonzalez-Polledo (2016) and Gonzalez-Polledo and Tarr (2016), explore the pain narratives – or 'pain worlds' – expressed on these platforms by individuals with chronic health conditions. According to their findings, these 'pain worlds' are potentially more efficient than traditional forms of pain communication in translating and communicating personal experiences of chronic pain. Tumblr's multimodal communication infrastructure also seems to enhance the emergence of a social dimension of chronic pain, where fragments of different life stories connect in narrative networks of pain (Gonzalez-Polledo, 2016).

The networked communication structures identified on Flickr (Gonzalez-Polledo and Tarr, 2016) and Tumblr (Gonzalez-Polledo, 2016) are also described in the limited research exploring health-focused Twitter streams as CoPs (Gilbert, 2016; Xu et al., 2015: 1362). As also seen in other online dedicated spaces (e.g. forums), these networked dynamics foreground some users among others: 'connectors, intermediaries or influencers designate those who act with a degree of vernacular authority to bridge professional and non-professional divides, establish and sustain supportive online communities and help to frame and re-frame others' experiences' (McCosker, 2018:4751). However, even in social media research applying the CoP paradigm, the actual fabric of health-focused streams, that is the potential combination of different types of knowledge within them, remains underexplored.

In sum, social media research has shed light on storytelling and its networked structures within communities interacting around personal narratives of health and illness, very much in line with what Akrich (2010) defines as 'communities of experience'. However, work aimed at exploring how health-related content is shared on mainstream social media platforms in general and Twitter in particular is still underdeveloped. In other words, is storytelling, namely a narrative process based on experiential knowledge of health and illness, the primary element used to talk about health on mainstream social media?

I argue that this question urges us to re-frame our understanding of health talk on contemporary social media with a renewed focus on the possible emergence of epistemic dynamics in the digital space. And a way to start is by developing our current understanding of social media issue publics.

## **Social media, issue publics and epistemic communities**

In 1964, American political scientist Phillip Converse introduced the notion of 'issue public', a concept that – 50 years later – was to become central to the study of public debate

on social media platforms. According to Converse's original 'issue public hypothesis' (Krosnick, 1990), institutional politics is hardly at the centre of citizens' everyday life as – due to time and resource constraints – citizens are most likely to get well informed on a very small number of issues. But how are these issues selected?

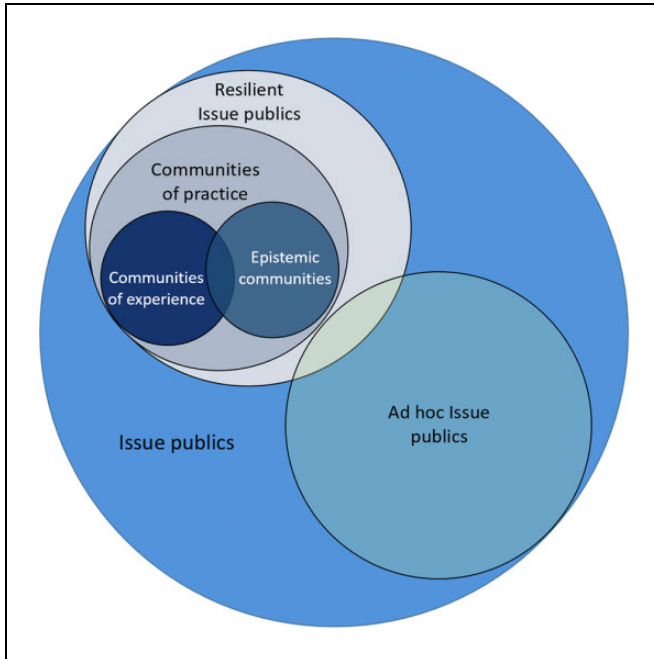
During a major event (e.g. economic depression, epidemic outbreak), most citizens form an opinion about that event and a large issue public emerges as a result of national – or global – resonance. In the absence of major events, however, citizens engage in much smaller issue publics, centred on issues that resonate more directly with their personal interests, the social group they identify with and their values (Krosnick, 1990). Hence, in ordinary conditions, an issue 'about which one citizen is passionately concerned is likely to be trivial to most others' (Krosnick, 1990: 74).

With digital platforms becoming ubiquitous in everyday life, the concept of issue public has turned central to investigating the discursive work developed by social media users. The attention has been almost exclusively drawn to Twitter conversations about major events and breaking news. In her study of the formation of issue publics in 2011 during the Egypt revolution and the US Occupy Wall Street movement, Papacharissi (2016) defines Twitter as a 'storytelling medium' that enhances affective exchanges. 'Affect is present in the rhythm and pace of storytelling, which is instant, emotive and phatic, frequently taking the form of a nod, a clap, a nudge, and other forms of affective expression' (pp. 316–317). Bruns and Burgess (2011) introduce the concept of 'ad-hoc publics' highlighting that 'What particularly allows Twitter and its hashtag communities to stand out from [...] other spaces for issue publics is its ability to respond with great speed to *emerging issues and acute events*' (p. 11, emphasis added).

Overall, Twitter research has mostly overlooked the core element of Converse's (1964) theoretical framing of an issue public: its mundane engagement with issues that are specifically central to the everyday of those involved. In other words, existing research tends to skim over the discursive work produced daily – in the absence of major events – by citizens engaging in discussions that directly resonate with their values, personal interests and social groups (Krosnick, 1990).

Linking back to Converse's (1964) original work, we can focus on Twitter affordances for what we may call 'resilient issue publics', that is publics emerging and developing over time on the basis of their members' personal experience of the issue at stake, in conditions *unrelated to emerging issues and acute events*. I argue that this shift is particularly relevant to health-centred social media threads because (1) health conditions are usually perceived as personal issues (Gonzalez-Polledo and Tarr, 2016), (2) health content is among the top searches on social media platforms (Pew Research Center, 2019) and (3) people use social media to connect with others in long-lived 'illness subcultures' (Conrad et al., 2016).

To be clear, resilient and ad hoc publics may temporarily intersect (see Figure 1), for instance, when a sudden event sheds light on an issue that is usually non-newsworthy (e.g. when a celebrity discloses information about a personal health condition), generating a peak of participation in the public debate about that specific issue. In other words, acute events throw ad hoc publics into resilient ones. However, I argue that by investigating mundane and resilient (i.e. long-lived) rather than ad hoc (i.e. heightened) conversations, we might be better placed to explore if and how contemporary social media platforms host



**Figure 1.** Twitter issue publics and epistemic communities.

epistemic dynamics comparable to those described in more traditional and enclosed online settings like dedicated forums, blogs or mailing lists (Akrich, 2010; Bellander and Landqvist, 2018).

In specific terms, this article takes two steps. First, it advances a conceptual framework (Figure 1) that allows one to explore the potential emergence of epistemic dynamics in platforms (e.g. Twitter) or platform areas (e.g. Facebook open groups) that require less personal commitment than the dedicated digital spaces investigated in previous research, for example, health discussion lists (Akrich, 2010) or carers' blogs and forums (Bellander and Landqvist, 2018). In other words, it allows one to test whether within the fluid *publics* – typical of these open contexts – *communities* may originate. Clearly, the communities we are referring to here are in *primis* 'discourse communities' as they emerge in a context characterised by a 'form of sociality in which language maintains a pivotal role' (Zappavigna, 2011: 789).

Second, it does explore empirically if and how these mainstream, relatively unbounded platform contexts – Twitter in particular – can enhance the emergence of epistemic dynamics, that is, enhance the intersection of the 'experiential' and the 'expert'. The analysis is then driven by the following research question:

RQ1. How and to what extent does storytelling, namely the narration of multiple and/or scattered personal life events, shape the content shared within resilient health issue publics on Twitter?

To explore in depth the potential intersection of experiential and expert knowledge in these publics, the study also advances a second research question:

RQ2. What are the sources of information used to produce this content?

## The BRCA resilient public on Twitter

This article addresses the research questions presented above by focusing on the discursive work produced on Twitter around the BRCA gene mutation – BRCA1 and BRCA2 – a hereditary condition that increases the risk of developing breast, ovarian and other types of cancer (National Cancer Institute, 2020). The condition became a topic of wider public interest when in May 2013 and March 2015 celebrity Angelina Jolie wrote in the *New York Times* about her choice to undergo preventive surgery due to being a carrier of the BRCA1 gene mutation (Jolie, 2013; 2015).

BRCA is a relevant case study for at least two reasons. First, previous scholarly work (Vicari, 2017) shows that the BRCA Twitter thread pre-existed Jolie's op-eds and continued its activity through the peaks (and the ad hoc publics) generated by the op-eds themselves. Hence, a resilient public has been feeding the BRCA Twitter thread since before 2013. Second, there is historical evidence of patient advocacy action involving expert knowledge related to the BRCA gene mutation. For instance, BRCA patient advocates were actively involved in the 2013 judicial case 'Association for Molecular Pathology versus Myriad Genetics' that challenged the legitimacy of pharmaceutical company Myriad Genetics' human gene patents (Carmody and Sartor, 2013).

## Methodology

As Welles (2014) sharply puts it, 'A large dataset quickly becomes small when you focus on a minority population'. By shifting the focus from volatile, highly populated 'ad hoc publics' (Bruns and Burgess, 2011) to fluid publics who resiliently engage with an issue intrinsically related to their everyday, this study requires making Big Data small and developing an explorative approach.

The analysis focuses on tweets mentioning the BRCA gene mutation during one month of activity unrelated to events of news value: 30 March–29 April 2017. Given the study's specific focus on the micro-dynamics of meaning production within Twitter's resilient threads, a one-month sample period was seen as a good compromise to provide an in-depth investigation of emerging epistemic processes.

Tweets were scraped live via Mozdeh using the keyword-based query 'BRCA',<sup>1</sup> able to retrieve tweets where 'BRCA' is mentioned in their text, in any embedded URLs or in a tweet they are replying to. The decision to rely on this query only was informed by Vicari (2017) work that showed the prevalence of the use of 'BRCA' in discussions specifically focused on the condition. The data scraping task returned 4049 tweets. Out of these, 482 were excluded because they were not relevant to the BRCA gene mutation', in a language different from English<sup>2</sup> or reporting unintelligible content (e.g. a broken URL), with the cleaned data set resulting in 3567 tweets. To be able to assess if, how and to what extent the BRCA resilient public shows the epistemic dynamics described in



Akrich's (2010) work, that is, the emergence and combination of personal accounts of health and illness and traditional medical information, tweets with content not explicitly delivering information about the BRCA mutations *as a health condition* (i.e. 20% of the cleaned data set) were further (manually) excluded. For examples of excluded tweets, please see Appendix 1.

Hence, the research presented in this article is based on a data set of 2848 tweets reporting information explicitly addressing the BRCA mutation as a health condition. The unit of analysis for this initial manual filtering and all the following analytical steps was the tweet, inclusive of its verbal and visual content and linked to external sources.

This article develops a methodological approach that navigates the relationship between Twitter and health topics by looking at the former as a socio-technical space and at the latter as issues for public debate (Marres, 2015). In specific terms, to investigate *how* and *to what extent* storytelling is used within the BRCA public (RQ1), I manually coded the sample to single out tweets incorporating elements of personal narrative as described in Orgad's (2005) work. This manual coding translated into reading the units, over and over again, to identify those incorporating 'a chain of events, ordered [...] along a timeline' or 'a framework that configures different events, actions and experiences into a plot' (Orgad, 2005: 37). As clarified in Orgad's (2005) original conceptualisation – and even more given the microblogging context investigated here – storytelling might 'not involve the actual creation of a final product (story) but still occupy a meaningful process, in that it allows participants to attempt to make sense of their experience in a certain way' (p. 39). In specific terms, I operationalised storytelling as the process of reporting at least a fragment of personal narrative in verbal or visual form as in the following paraphrased text posted by User 4:

'I am a survivor, my mum and sister passed from it I have BRCA1 Glad you are fine [heart]'

or in the picture tweeted by US celebrity Lesley Murphy shown in Figure 2.



**Figure 2.** Visual storytelling.

With storytelling units having been identified, I conducted a qualitative analysis of intertextuality across storytelling and non-storytelling units. Intertextuality focuses on the way texts are formulated on the basis – and in anticipation – of other texts (Fairclough,

**Table 1.** Information source codebook.

| Source Category                         | Source Subcategory                        | Example   |
|---|---|---|
| Traditional academic source             | Academic journal                          | <i>bmj.com</i>  |
|   | Academic blog portal                      | <i>blogs.plos.org</i>   |
|   | Research centre                           | <i>brca.ucsf.edu</i>  |
|   | University                                | <i>bu.edu</i>   |
|   | Academic conference                       | <i>#AACR17</i><br><i>ascopost.com</i>   |
| Medical news (professional audience)    |   |   |
| Health news (non-professional audience) | News outlet                               | <i>breastcancer-news.com</i>  |
|   | Blog portal                               | <i>breastcanceryogablog.com</i>   |
| Other topic-focused news                |   | <i>afr.com</i> (finance)  |
| Generalist news                         | News outlet                               | <i>abcnews.go.com</i>   |
|   | Blog portal                               | <i>30 seconds.com</i>   |
|   | Social news aggregator                    | <i>mashable.com</i>   |
|   | Magazine                                  | <i>jlfemagazine.co.uk</i>   |
|   | Blog portal hosting first-person accounts | <i>hummingbirdlingerie.tumblr.com</i>   |
| First-person                            | Personal social media                     | <i>Individual's Facebook page</i>   |
|   | Personal website/blog                     | <i>ellendolgen.com, wormsinmysalad.com</i>  |
|   | Personal photo                            | <i>Selfie that shows surgery scars</i>  |
|   | Online community                          | <i>#GenCSM</i>  |
|   | For profit (medical/pharma) organisation  |   |
| Non-profit organisation                 |   | <i>aclu.org</i>   |
| Source not mentioned                    |   | <i>'@User_3 If ovarian cancer runs in your family you should consider being tested for a BRCA mutation' (paraphrased)</i><br>Author: User 1 |

1992). Intertextuality links are linguistic markers that relate a text to a source (e.g. via a citation) or indicate an author's stance towards that source. In so doing, they provide insights into the way authors position themselves in relation to the information they share.

To shed light on the sources of information used within the BRCA public on Twitter (RQ2), explicit references (e.g. external webpages linked to the tweets containing URLs, pictures of conference posters) were extracted (see 'Example' in Table 1) and inductively grouped on the basis of their original mission and – where relevant – target audience (see 'Source Subcategory' and 'Source Category' in Table 1).

This second coding was aimed at providing an overall mapping of the sources of information referenced by the members of the BRCA resilient public. By qualitatively discussing the relationship between these sources and the tweeters using them, I then further unpacked how experience and expertise intersect and manifested in the public. With both coding tasks having been completed, coding output was verified against

codebook definitions of storytelling and source categories (Table 1) in a form of input versus output verification (Franzosi, 2004: 78). Indeed, the small-scale and primarily qualitative nature of this work limits the generalisability of its findings. They, however, also lead to results that could inform future research interested in broader, longitudinal patterns of knowledge production in mainstream social media environments.

Given its focus on stories of health and illness, attention to ethics has guided each stage of the study. In this article, I only refer to original Twitter handles of – and content posted by – organisations, public figures and individuals who have publicly spoken of their engagement with BRCA advocacy outside Twitter. This rationale was driven by the fact that the research questions addressed here do not require disclosing further personal information – and potentially cause the ‘undue harm’ mentioned by social media users in previous research (Beninger, 2017: 67). Where none of the abovementioned conditions were met, handles were replaced with pseudonyms (e.g. User x) and tweets paraphrased, in line with Townsend and Wallace’s (2016) discussion of privacy and risk in social media research (p. 10–15).

Paraphrasing units of analysis in a discourse analytic framework is indeed a risky process. Given the focus on intertextuality, the risk was contained by keeping the original intertextuality links in the paraphrased tweets. To reproduce the original vernacular of anonymised tweets, I created a fictional Twitter account with handle ‘User x’ and posted the paraphrased tweets on the platform, setting this content as not publicly available. The article presents screenshots of these tweets.

## **Stories, non-stories and intertextuality in the Twitter BRCA thread**

For over two decades, storytelling has been explored as central to the understanding of how we write and learn about health and illness online (see, for instance, Hardey, 2002; Orgad, 2005). This study’s findings, however, seems to suggest a slightly different story.

Coding results show that the BRCA resilient public is more than twice as likely to produce content that excludes rather than includes instances of storytelling (Table 2).

What is more, tweets delivering fragments of personal narratives are rarely first-person accounts. In fact, more than 70% of these tweets are the result of automatic or semi-automatic sharing (Table 2), hence messages relaunching someone else’s story. These practices in themselves can be seen as a form of intertextuality: a text is being selected and re-presented in the same context (i.e. retweeted) or in a different one (i.e. button shared from their original webpage). The positionality of these tweets’ authors, however, remains ambiguous: while enhancing the visibility of BRCA content, these authors do not invest in commenting on, expressing an opinion about or reshaping it. In other words, via these automated sharing practices, tweeters can draw attention to the BRCA ‘subculture’, without having to expose their own relationship with BRCA or – where relevant – their ‘self-story’ (Orgad, 2005) as part of the BRCA subculture itself.

When authors visibly engage with the stories they tweet (i.e. via original messages), they use different forms of intertextuality to position themselves in relation to the content they share. User 3 (Tweet 1), for instance, a seemingly ordinary user, expresses intimacy with the subject at the centre of the story they share by addressing them as ‘a friend of mine’. Similarly, the non-profit organisation Hereditary Cancer expresses sympathy for US media

**Table 2.** Personal storytelling and communication practices in the sample data set.

|                     |             | Communication practice   |                          | Grand Total |
|---------------------|-------------|--------------------------|--------------------------|-------------|
|                     |             | <i>Original tweeting</i> | <i>Automated sharing</i> |             |
| <b>Storytelling</b> | <b>yes</b>  | 268 (28.42%)             | 675 (71.58%)             | 943 (100%)  |
|                     | <b>no</b>   | 636 (33.39%)             | 1,269 (66.61%)           | 1905 (100%) |
|                     | Grand Total | 904 (31.74%)             | 1,944 (68.26%)           | 2848 (100%) |

celebrity Lesley Murphy ‘for her public display of bravery’, namely for narrating her BRCA self-story on her Instagram account (and other media outlets) (Tweet 2). Twitter vernacular also allows Hereditary Cancer to visualise this closeness with the ‘two hearts’ emoji, here working as a ‘marker of emotion’ (Bellander and Landqvist, 2018: 5), used to emphasise affect. Hereditary Cancer, however, like the collective account Genomic Alliance (Tweet 3), also relies on this storytelling to raise awareness on a BRCA-related issue (e.g. cancer preventive surgery in Tweet 2 and male breast cancer in Tweet 3).

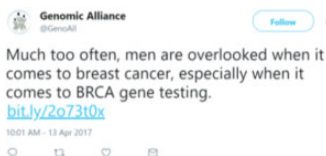


This is a nice piece written by a friend of mine, on facing challenges and confidently fighting back.  
[medium.com/@sazcoaster/ble ...](https://medium.com/@sazcoaster/ble...)

Tweet 1 (paraphrased). [URL to Koster, 2017]



Tweet 2

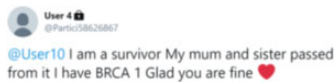


Tweet 3. [URL to Tucker, 2016]

This use of third person storytelling resonates with Trevisan’s (2017) findings on the ever-growing ‘advocacy technique of [...] crowd-sourcing, organizing, and disseminating personal life stories online’. It also further points to the need to explore health storytelling from a perspective able to address the different levels of both publicness and mediation characterising the contemporary media ecology. This will be further discussed in the next section.

Given that less than one-third of the storytelling tweets are original messages (see Table 1), first-person accounts of health and illness are obviously not common. However, among these, it is possible to identify iconic instances of storytelling, where fragments of life events are related together to draw a story along a temporal continuum (Orgad, 2005). User 4, for instance, microblogs her BRCA self-story and uses it with the ‘heart’ emoji – again a marker of emotion – to express sympathy to User 10 (Tweet 4).

Traditional storytelling can, however, evolve in very different ways. It is not uncommon, for instance, to come across storytelling engraved in ‘influencer’ work. Lesley Murphy (Tweet 5) live streams her BRCA self-story, reshaping her ‘coherent branded identity’ (McCosker, 2018: 4752) around it. Intertextuality here allows Murphy to mention @uamshealth, (i.e. the University of Arkansas for Medical Sciences, where the surgery supposedly took place) and hop with her readers on to her Instagram account for the live streaming of her BRCA self-story (Tweet 5).



Tweet 4 (paraphrased).



Tweet 5. [URL to Murphy, 2017]



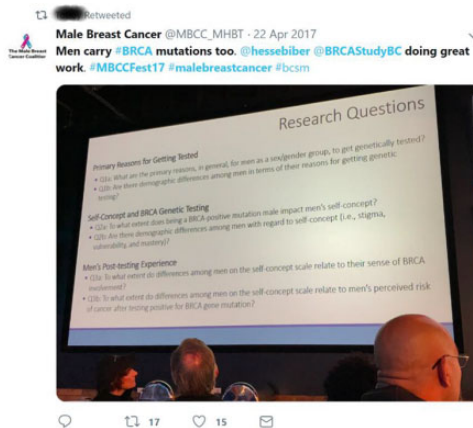
Tweet 6 (paraphrased).

In some cases, first-person storytelling manifests itself in subtler formats. In Tweet 6, for instance, ‘I am BRCA 2’ translates into a series of unsaid events, namely ‘I experienced cancer (directly or via a member of my family), I did a

genetic test, I found out I have the BRCA 2 gene mutation’. The accent here is, however, not so much on those scattered events, their sequence or the actors who participated in them; it is on what follows in the tweet: ‘I believe gene therapy is our hope for the future’. In fact, storytelling is here functional to frame the author’s identity and ‘lay expertise’ (Hardey, 2002). In other words, User 5 is saying: ‘I am x, hence I am entitled to say y’.

Most tweets reporting content different from personal storytelling directly draw upon external sources (e.g. conference presentation in Tweet 7 and journal article in Tweet 8), with authors again usually (i.e. 67% of the times, see Table 2) either retweeting existing content (Tweet 7) or sharing URLs via the Twitter share button on external webpages (Tweet 8; Figure 3).

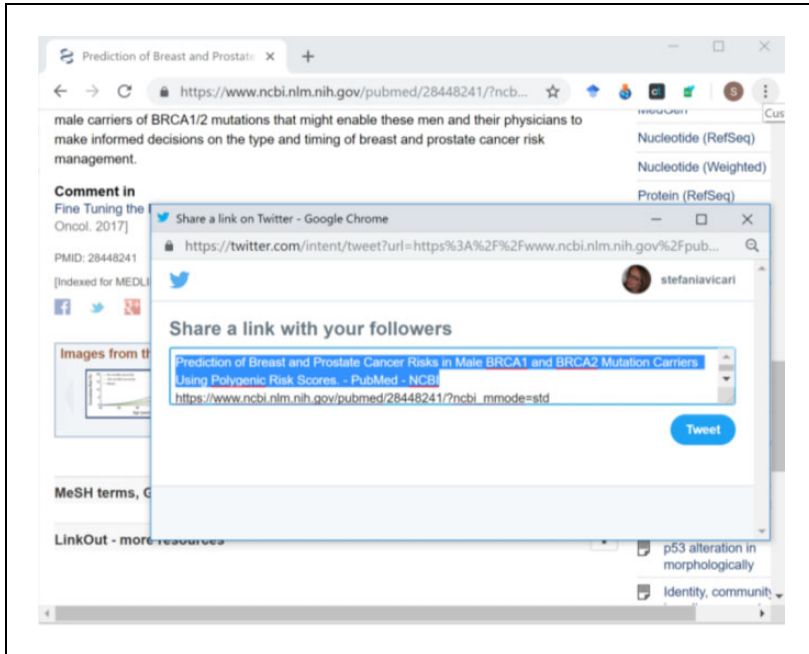
It is interesting to notice that while relying on these platform-automated or semi-automated sharing dynamics, authors sometimes engage in active textual crafting by, for instance, inserting hashtags (#BreastCancer, #ProstateCancer, #BRCA and #Genetics in Tweet 8 but not in the automatically generated text shown in Figure 3) or deleting bits of the original text (e.g. ‘– PubMed – NCBI’ in Figure 3 but not in Tweet 8).



Tweet 7.



Tweet 8. [URL to Lecarpentier et al., 2017]



**Figure 3.** Tweet 8's button sharing from the original webpage.

In entering or navigating the twittersphere via these automated or semi-automated sharing practices, non-storytelling content is then often simply synthesized and translated in a way to comply with – and make the most of – platform norms. In this transition, traditional ‘markers of direct reference’ (Bellander and Landqvist, 2018: 5) – that is, linguistic devices that indicate where pieces of information come from and how authors relate to them – are replaced by what we may define as ‘platform markers of reference’, for example, shortened URLs and hashtags. These new markers, however, are more likely to prioritise content visibility and outreach over source visibility and author’s stance. Shortened URLs, for instance, make space for more substantial tweet content while using multiple hashtags makes tweets retrievable by different ‘discourse communities’ (Zappavigna, 2011).

Where authors engage more explicitly with the external content they share (i.e. in original tweets), interpretive dynamics surface more clearly (Tweet 9). User 6, for instance, comments on the piece of news reported at the tweeted URL, namely a proposed bill that would allow companies in the United States to collect genetic information from their employees.



Tweet 9 (paraphrased). [URL to Begley, 2017]

The author's stance towards the bill is delivered via the use of vernacular devices that express sarcasm, namely the hashtag #ICYMI (i.e. 'in case you missed it') and the repeated 'pensive face' emoji. In this case, then, platform norms add to the effect of traditional markers of emotion (i.e. the ellipsis mark), providing additional and accentuating devices to express affect and attitudes.

In sum, stories and non-stories intersect in the BRCA Twitter thread, with storytelling playing less of the central role described in previous digital and social media research. In sharing and/or engaging with this BRCA content, the BRCA public develops different forms of platform-enhanced intertextuality. But what actual sources of information are most commonly used within the public itself? Who introduces these sources to the public? The following section will address these questions.

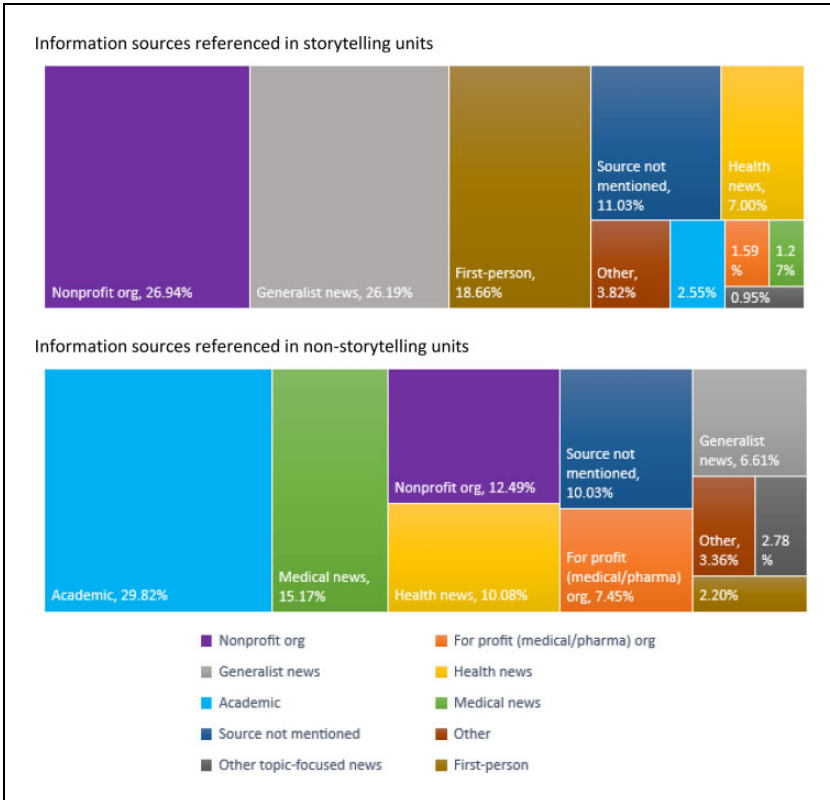
## Information sources navigating an ecological system

What often gets blurred in a microblogging environment is where the information being shared on the platform originates from. Figure 4 maps sources of information across storytelling and non-storytelling units.

When it comes to the use of BRCA stories, more than one-fourth (i.e. 27%) of the relevant tweets reference non-profit organisation websites, with generalist news media being almost equally relevant (i.e. 26%). Among the top 10 tweeters most often referencing these sources, 5 are advocacy organisations themselves (i.e. Facing Our Risk of Cancer Empowered, Male Breast Cancer Coalition, Men Have Breasts Too, National Hereditary Breast Cancer Helpline and Breast Advocate) with the rest being individual users. Again, this points to the centrality of 'crowdsourced storytelling' in contemporary advocacy action, as recently stressed by Trevisan (2017): 'Advocacy and activist groups [...] develop new techniques to influence public debate and policy decisions, using the Internet to crowd-source, organise, and disseminate their constituents' personal stories' (p. 192).

Overall, in storytelling units referencing external sources, the voice of the individuals whose story is being told – that is, that of the initiators of these stories themselves – navigates different layers of mediation before reaching Twitter. In fact, it might not be surprising that Lesley Murphy's preventive mastectomy enters the twittersphere via her blog (Tweet 2), her Instagram account (Tweet 5) and a number of generalist news media (e.g. *People*. See Stone, 2017). As a matter of fact, as a media celebrity, Murphy engages on a daily basis in self-branding tactics that require a certain level of personal disclosure and 'context collapse' of social media activity

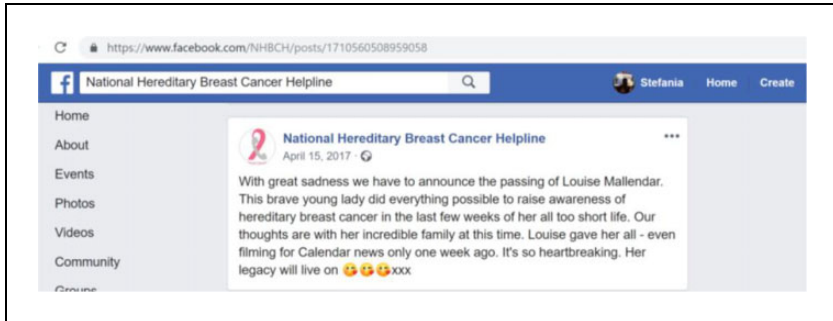




**Figure 4.** Information sources.

(Khamis et al., 2017: 195). This ecological dimension, however, also characterises the narration of ordinary citizens with extraordinary stories of health and illness. Louise Mallendar’s story gives us a glimpse of this.

On 28 March 2017, Snow Elk Productions published a video on their YouTube channel for National Hereditary Breast Cancer Helpline (NHBCH) where Louise Mallendar recounts her story as a 36-year-old terminal cancer patient with BRCA 1 mutation.<sup>3</sup> In the video, Louise walks her audience through the different phases of her condition, describing both its impact on her family and her relationship with the medical information and the physicians involved in her diagnosis and treatment. The video first appears in the data set on 30 March in a retweet by an ordinary Twitter user and reappears on 5, 6, 7, 8, 9 and 11 April, when it also gets incorporated and commented on in an Itv news webpage (Itv news, 2017), quoted in a NHBCH tweet. The video reappears on 12 and 13 April. On 15 April, NHBCH tweets its own Facebook post announcing Louise’s passing (Figure 5), being then retweeted by a number of BRCA patient advocates.



**Figure 5.** NHBC Facebook post announcing Louise Mallendar's passing.

Differently to Murphy's case, each digital artefact bringing Louise's story onto Twitter (i.e. video on Snow Elk Productions YouTube channel, piece on Itv news webpage and post on NHBC Facebook page) plays a different role in building BRCA awareness (and knowledge): Snow Elk Productions YouTube video – and its virality – make BRCA newsworthy, the piece on the Itv webpage widens BRCA visibility and the NHBC Facebook post strengthens ties among BRCA advocates. This intersection of actors (Louise, NHBC, Snow Elk Productions, Itv news, users tweeting about Louise) and platforms (YouTube, Twitter, Facebook, Itv webpage), however, also generates a complex network of sources of information that is hard to untangle outside an ecological prism.

Moving on to non-storytelling units, Figure 3 shows that 45% of the tweets relying on non-narrative content draw upon either academic sources or medical news aimed at a professional audience. This means that between 30 March and 29 April 2017, one-third of the tweets reporting information relevant to the BRCA gene mutation as a health condition directly referenced traditional sources of medical expertise. But who are the authors behind these tweets, namely the providers of this scientific information?

The top four – and, overall, 6 out of the top 10 – users most often referencing academic sources or medical news in their tweets are patient advocates with a substantial follower base who 'self-tag' with a series of cancer and hereditary cancer hashtags (i.e. #bcm, #BRCA, #breastcancer, #GenCSM, #geneticstesting, #gynccsm, #hereditarycancer, #Lynchsyndrome, #NSGCgenepool and #PancChat) (Table 3). In fact, among the top 10, only one identifies herself as a medical doctor.

These final findings clearly show that a number of individuals who would be traditionally identified as *lay* actors are key providers of scientific information within the BRCA-resilient public on Twitter. In other words, their engagement with both the public and the platform translates into foregrounding their experiential knowledge and also acting as gatekeepers of traditional expert information.

**Table 3.** Top four users quoting scientific sources or medical news.

| Author              | Followers<br>(April<br>2017) | Twitter bio (May 2020)  | Evidence of patient<br>advocacy |
|---------------------|------------------------------|---|---------------------------------|
| Lisa M Guzzardi, RN | 4857                         | #PatientAdvocate providing up to date research for 3 K + consumers @ risk & clinicians #JournalClub #bcsn #gynscn #PancChat #BRCA #hereditarycancer #NSGCgenepool | Nawrat (2019)                   |
| Amy Byer Shainman   | 4909                         | Education - Advocacy - Support #BRCA #hereditarycancer Advocate-Author-Producer @pinkandbluedoc @GenC_SM #NSGCgenepool Consulting Producer @LadyParts_film        | Byer Shainman (2019)            |
| Karen Lazarovitz    | 4011                         | Creator #BRCA Sisterhood & Supportgroup #Montreal #breastcancer #hereditarycancer #geneticstesting #publicspeaker my story #mastectomy #tattoos link below        | Kalinowicz (2019)               |
| Georgia Hurst       | 6452                         | Fierce advocate for those with #Lynchsndrome. #MissObama.#Microbiome #Lynchsndrome #GenCSM.   | Hurst (2019)                    |

## Discussion and conclusion

Stories matter, but they are not all that matters on social media platforms. By questioning the centrality of storytelling in health-centred threads that develop over time on these platforms, this study explores the epistemic dimension of mundane social media uses centred on health issues.

Perhaps not surprisingly, the BRCA Twitter public presents extensive informational practices, as partly shown in previous studies of Twitter health CoPs (Gilbert, 2016). What, however, is novel in the findings presented here is that these practices are more likely to rely on non-storytelling information than on personal narratives and are highly shaped by and adapted to platform norms. When storytelling does appear, it is more often based on third-person narrations than on 'self-stories' (Orgad, 2005). These 'stories of others' are shared on the platform to give visibility to their authors and/or to a specific aspect (i.e. the use of preventive surgery) of the BRCA

‘subculture’ (Conrad et al., 2016). First-person accounts show similar features to those of the storytelling practices discussed in previous research (Orgad, 2005), though adapted to a microblogging context.

In fact, the platform context impacts both storytelling and non-storytelling processes. In particular, the platform vernacular foregrounds tweeters’ and content visibility over reference: it widens the range of markers of expression (e.g. emojis), enhances markers for outreach (e.g. hashtags) and decreases the meaningfulness of markers of reference (e.g. shortened URLs as opposed to traditional citations). Hashtags, while making tweets retrievable by different ‘discourse communities’ (Zappavigna, 2011), also mark authors’ expertise, namely their ‘*knowledge of the practice, the discourse, and the group’s worldview*’ (Brock, 2012: 539, emphasis added).

Overall, this first set of findings clearly show that, contrary to what happens in more dedicated digital spaces (e.g. user lists, patient or carer blogs or forums), Twitter users can easily rely on the platform’s affordances to disclose – or *not disclose* – their ‘personal commitment’ (Akrich, 2010) to the BRCA thread and – where relevant – their BRCA self-story. This fluidity then allows – and legitimises – loose forms of participation in the BRCA public and the BRCA subculture itself, offering ways of engagement for those unwilling to share personal narratives or show strong commitment.

Findings on the actual information sources referenced in BRCA tweets show that BRCA ‘stories of others’ are mainly borrowed from non-profit organisation websites and generalist news media for advocacy purposes (Trevisan, 2017). The voice of those living and initiating these stories – *lay* individuals made expert by their BRCA story (Hardey, 2002) – travels through different layers of mediation and becomes exemplar within the BRCA subculture.

A large portion of non-narrative content directly references traditional scientific sources, with patient advocates acting as key providers of this content. While sharing features (e.g. their digital labour) with the health influencers described in previous research (McCosker, 2018), these individuals act more as gatekeepers of scientific information than as social media ‘microcelebrities’ (Abidin, 2016). In other words, they develop influence by regularly foregrounding selected sources of information rather than building a 360 degree persona ‘through empathy practices that sustain impactful connections’ (McCosker, 2018: 4761).

To conclude, the study shows that in the BRCA Twitter public, the ‘experiential’ and the ‘expert’ intersect in varied forms of mediated and unmediated discursive work that incorporate both storytelling and non-storytelling content. At the heart of this intersection are ‘lay experts’ who initiate BRCA stories, become exemplars within the BRCA subculture or act as gatekeepers of scientific information. In fact, what is missing in the picture is the presence of ‘specialists on the question in different ways’ (Akrich, 2010), in this case, traditional scientific actors. These findings suggest further work in two directions. First, research could explore scientists’ understandings of and attitudes towards social media as a potential means to collaborate in both the integration of lay and scientific expertise and the gatekeeping of quality information. Second, future studies

could look into if, how and to what extent patients - as lay experts - could contribute to platform health-related moderation policies.


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### Notes

1. Mozdeh accesses tweets via Twitter search API. This API cannot return more than 1% of the total number of tweets posted at the time of data collection, but this obviously does not constitute an issue for the present study. The search API also removes an unspecified number of other tweets, but alternative APIs are hardly accessible due to platform restrictions (e.g. Historical PowerTrack API) (Twitter, 2020). However, research has shown that the search API tweet removal is only likely to be problematic for research specifically focused on spam detection (Thelwall, 2019).
2. I decided to only focus on English tweets as the identification of intertextuality links across languages is not an objective of this study.
3. The video is available at: <https://www.youtube.com/watch?v=hEU8IzGUmV4>

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## Appendix I

| Content type              | Definition   | Exemplar   |
|---------------------------|--|--|
| Question                  | Asking questions about BRCA-related issues.  | '@BCSMChat Is it normal to wait 5 weeks for a mastectomy for #TNBC IDC? #bcm' (paraphrased)<br>Author: User 11   |
| Live coverage of an event | Live coverage of a BRCA-related event.   | 'What do BRCA carriers experience? Research by (my wonderful friend) @participant and her JOGC article being presented! #Gcchat #cardiffGc' (paraphrased)<br>Author: User 12                       |
| Social interaction        | Showing positive affect such as appreciation, greeting and congratulations; showing interpersonal closeness; aimed at developing relationship.                       | 'Soup's on. Happy Passover from our @MBCC_MHBT family. #malebreastcancer #menhavebreaststoo #brca #bcm https://t.co/bl8j1Brvff [picture]'<br>Author: User 13                                       |
| Advocacy                  | Prompting receivers to take actions such as signing petitions, making donations or checking information on advocacy website; recounting advocacy actions and events. | '£5,402.17 raised at BRCAfest 2017! We also shared a lot of information of #BRCA and #ovariancancer. URL [pictures]' (paraphrased)<br>Author: User 14  |
| Event invite              | Inviting to a specific event (e.g. conference, advocacy event)   | '#UntanglingTheHelix @10:25 am at #CPDrefresher2017 @CME_UOTTAWA @UofODFM find us in the main room 106 C-G for more on #BRCA, #LQTS and #DTC https://t.co/gz7c922QmK [picture]'<br>Author: User 15 |

Exemplars of excluded tweets. Codes were generated by drawing upon Xu et al.'s (2015) codebook and inductively adjusting to the BRCA data set.