Co-constructed health narratives during a 'media event': The case of the first Dutch Twitter heart operation

Samantha Adams[1] and Puck Schiffers[2,3]

Abstract

Objective: This article examines the relationship between microblogging and the development of health narrative through the lens of an institution-initiated media event, the first live-tweeted heart operation in the Netherlands. It specifically addresses the question, how does health narrative take shape on a microblog and other (social) media, through the combination of self-initiated status updates, reactions to questions and short conversations with followers?

Methods: A combination of qualitative and quantitative data analysis was used to identify prominent themes in the tweets and trace the complex process by which the narrative took shape. The results presented here are derived from the qualitative analysis.

Results: There are four recurring health narrative themes in the tweets: (a) new challenges to professionalism; (b) mutual exchanges of information, support and advice; (c) increasingly personal (and public) details; and (d) questions about 'resuming normalcy'. The special nature of this case also reveals interesting features, such as the multiple narrative starting points and the phenomenon of 'tweeting by proxy', and raises a number of critical questions regarding this type of use of social media in healthcare.

Conclusions: In the discussion we reflect on whether/how microblogged health narratives are really 'new' and on the implications of this single case for understanding the relationship between social media, health narrative and the changing relationships between information technologies, actors and institutions. We further examine this case as an example of what Lupton has deemed the 'digital patient experience economy', in reference to patients increasingly being encouraged to post experiences of their illness and encounters with the healthcare system to online platforms, where these shared experiences become valorised and monetised.

Keywords

Social media, microblogging, twitter, health narrative, mixed methods

Introduction

In 2012, a non-academic hospital held the first heart operation broadcast live via Twitter in the Netherlands. A cardiologist partnered with a medical journalist to create this event, which was first announced at a 2011 national symposium promoting innovation in healthcare. In preparing for this announcement, the cardiologist interviewed several patients about their experiences with their condition, the care system and themes related to innovation.

One of these patients (age 45 years) had an operation pending and (when asked by the physician) indicated interest in tweeting about the process. As the patient

[1]Tilburg Institute of Law, Technology and Society, Tilburg University, the Netherlands
[2]Erasmus University Rotterdam, the Netherlands
[3]Deloitte Amsterdam, the Netherlands

Corresponding author:
Samantha Adams, Tilburg Institute of Law, Technology and Society, Tilburg University, Room M-720, PO Box 90153, 5000 Le Tilburg, The Netherlands.
Email: s.a.adams@uvt.nl

later indicated in tweets to journalists, the interest in tweeting publicly was a result of the impact that the condition in question had on his/her daily life. The patient felt that other patients should be informed about possible solutions through first-hand experience. After several discussions about the potential consequences of widespread publicity (such as possible invasion of the patient's privacy), the heart centre and the patient decided to move forward with the project.

The patient, members of the cardiology team (physicians, nurses and technicians) and hospital administrators (division manager, appointment planner), none of whom were active on social media at the time, created Twitter accounts especially for the event. The medical journalist explained the basics of 'tweeting using an iPad' to the patient, who (in early tweets) indicated having never tweeted and rarely sending text messages. In the weeks immediately preceding and following the operation, both the patient and the surgeon tweeted about the process and answered questions posted on the Twitter feed. One of the hospital's surgical assistants tweeted about the procedure *in situ* and posted pictures to the Twitter feed and the photo-sharing site Flickr.

Newspapers carried headlines that the Twitter community was morally supporting the patient and regional and national television programs carried a short news spot about the event. At the time of the operation, the cardiologist and patient each had ±900 followers (mostly from the region where the hospital is located); 1.8m Twitter users followed the live event.

This article examines the relationship between microblogging and the development of health narrative through the lens of this institution-initiated media event. It specifically addresses how this health narrative took shape on a microblog (Twitter) and other (social) media before, during and after the event, through the combination of patient-initiated status updates, questions from 'followers', reactions (on both Twitter and in other media) and online conversations between various parties. After a brief review of microblogging, we discuss health narrative in relation to the web. We then describe the methods of analysis for this single case study and analyse the content of the narrative, partially topically and partially temporally, in order to show the complex process by which narratives developed in this case. In the discussion, we address whether the identified characteristics of microblogged health narratives are really 'new'. We conclude with a reflection on the implications of this single case for understanding the relationship between social media, health narrative and changing relationships in healthcare, specifically following Lupton's critique of the rising 'digital patient experience economy'.[1]

Microblogging

Although microblogs have been around longer, microblogging as a social activity has increased in popularity since the launch of Twitter in 2006. One of the features most commonly used to define microblogs is their brief messaging design: platforms impose a maximum length for each communicative utterance, such as Twitter's 140-character limit for a single tweet.[2] By asking participants, 'What's happening?', microblogs are broadcast media with a dialogic nature that provide an arguably constantly updated stream of short messages with various forms of content.[3] Microblog messages also have technology-specific characteristics: using '@' addresses a tweet to a specific user (called an 'at reply'), adding '#' ('hashtag') to one or more (meshed) words creates keywords and makes tweets searchable by topic, and starting with RT indicates that a tweet was originally posted by someone else and is being re-tweeted.

Media and communication scholars are interested in how such specific technical rules, unconventional grammar and unique syntax alter communication patterns and interactions between individuals and groups.[2,4,5] Much work has been done in computer science to 'mine' Twitter for e.g. health or political sentiments. Health research has addressed how mined tweets may be used for population-level disease surveillance,[6–8] as an educational tool,[9,10] or for institutional media 'events' such as live broadcasts of surgery.[11,12] Some studies[13,14] have examined the quality of health information exchanged in such tweets. However, to date, there are no known studies specifically focused on how health narratives unfold in the series of tweets.

Increased use of Twitter for health-related communication offers new opportunities to examine how microblogging platforms influence both the content and process of health information exchange. As Lee and Sundar indicate,

> Just as health messages in Twitter do not appear in isolation (they will invariably share the feed with other, non-health tweets), the microblogging platform itself does not exist in isolation. Twitter is intertwined with a whole host of traditional [and] newer social media, drawing upon websites for its sustenance, and is therefore one among a growing chain of online sources (p.520).[6]

Various terms have been attributed to the 'narrative' of microblogged status updates. Karim[15] refers to 'micro'-narrative, owing to the technology and the practice of microblogging. Similarly, Stephansen and Couldry[16] discuss the importance of understanding 'micro-processes' on Twitter through a 'small data' approach. Marwick and Boyd,[17] by contrast, suggest that such

communicative utterances reflect the commodification of the conscious, whereby they actually form a 'meta'-narrative. Whether it is 'micro' or 'meta', research is beginning to suggest that online narrative is either changing in part through microblogging practices or being re-qualified in relation to existing interpretations of what narrative is.

In this article, we consider this possible change in narrative on two levels: (a) social media *in general* as the next step in information technology development which incrementally shapes, and is shaped by, (health) narratives and (b) the microblog as a *specific type* of social media, where a narrative is produced that does not easily fit into current narrative categories. For example, status updates in the moment means that the interface is not static (as posted pictures or videos might be), but ever-changing; not retrospective and reflective (as blogposts and home pages often are), but current and (potentially) prospective. As is further described below, microblogs are all of these at once: stimulating real-time status updates, constantly and dynamically changing with information about the here and now, the past and the future. But what is the nature of such information? What (parts of) tweets or feeds count as health narrative and how is this narrative co-constructed by the twitter user, his/her followers (including patient peers, health professionals, family and friends), imagined other audiences and the technical medium? How does this narrative reflect elements of the emergent digital patient experience economy? In order to answer these questions, we first contextualise the development of health narrative through microblogging in a longer tradition of studying health narrative, both offline and online, before delving into the case.

Co-constructing health narratives and the web

Focus on (illness) narratives has been a key feature of much medical sociology.[18] Historical studies pinpoint the 1970s and 1980s as the starting point for socio-logical and anthropological interest in patients' narra-tives of health and illness.[19–21] Patient accounts are valuable for understanding the physical and emotional changes related to illness[20] and provide a broader pic-ture of illness that incorporates related aspects, such as physical, emotional and social changes.[22] Narratives are anchored in how illness may disrupt personal plans and structures of the everyday,[23] as well as in the expectations associated with what has been called the 'sick role'[24] and how medicine provides a cure or treatment for it.[18] Frank[25] has shown the latter as part of the restitution narrative, whereby treatment eventu-ally leads back to 'good' health, but he also identifies other aspects of narrative, such as the quest narrative,

where an individual believes there is something to be gained in the illness experience. According to Nettleton and Hardey, illness may then become a medical journey leading to self-awareness or the desire to help others.[26]

Studies of health narratives generally focus not only on content, but also on how they are produced by and with patients, for various purposes and in different types of settings, including how information is relayed during the consultation. Formation of narrative is gen-erally recognised as being at least partially structured by the setting of the medical encounter and the inter-action between patients and health professionals,[27] or between patients, their loved ones and professionals.[28] Gibson[29] also discusses the role of researchers in con-tributing to the structure and shaping of health narratives.

Narrative reconstruction[30] is therefore currently understood as being co-produced, with 'co-production' pointing to various constellations of interactions between human and non-human actors. The (re-)telling of a story can also occur outside of the medical encoun-ter, in a variety of social situations, including computer-mediated environments (notably, personal websites, weblogs and other social media that provide a space where individuals can articulate their experiences, per-ceptions and understandings). Understanding health narrative therefore also necessarily includes the exam-ination of such spaces.[31]

According to Hine,[32] the most prominent social sci-ence framework for analysing web pages has been to view them as a form of construction of the self. Often drawing on Goffman's theories[33] of identity and social performance, researchers have examined why individ-uals create personal websites and which strategies they employ to develop their digital self-presentation. Schau and Gilly[34] note that digital self-presentation on a per-sonal website enabled *reorganising linear narrative structures*. That is, the act of hyper-linking broke down the hierarchy of linear writing and allowed indi-viduals to tell their stories with specific points of elab-oration made available to the reader through the act of clicking on a given hyperlink. According to Schau and Gilly, this meant that narratives had no distinct begin-ning, middle or end, but rather multiple modes of elab-oration, indicating both *spatial* and *temporal* shifts in narrative.[34]

Hine criticises approaching web pages merely as textual identity performance, which potentially over-looks the processes through which production is made *socially meaningful*.[32] She argues that we must examine web pages in relation to both online and offline con-texts, thereby considering how performances are imbued with understandings of what the technology is and how it fits the author's goals. Studies of the role of the Internet in shaping health narrative must therefore

extend the idea of co-production to include the role of technological interfaces and the symbolic formations they allowed (avatars, metaphors, images, hyperlinks, etc.), as well as the real and imagined audiences of narratives being produced.

Hardey conducted one of the earliest studies[31] of how health narrative takes shape on the web by examining how individuals used online spaces to rewrite their biographies and transform their social networks. He viewed homepages as a 'uniquely personal way of remaining part of a community and benefitting from social support through email and other resources' (p.36) and a space where authors constantly evaluated (and at times challenged) expert knowledge. He analysed these sites along two axes: how authors saw themselves and why they constructed an online narrative. Through this examination, he identified four categories of web-based health narrative: the personal story and explanation, the personal story and advice, the personal story and offered solution, the personal story and offered products or services. He saw that authors often (but not always) proceeded through these categories during their illness trajectories, starting with just the story, then proceeding to give advice based on their experiences, followed by promoting specific health regimes or solutions (arguably as a surrogate for professional expertise) and finally, to developing their own products/services. His work provided one of the first descriptions of the online narrative project as inherently dynamic, interactive and unfinished, and demonstrated how hyperlinks were used to connect an individual's personal story to resources that justified his/her standpoint (especially when advice and solutions were embedded in narrative).

This movement from explaining to providing products/services to *potential* readers is an important component of online health narrative and became more pronounced as web interfaces evolved. The act of constructing narratives of the self (including health narrative) in online spaces is increasingly influenced by (perceived) demands of both real and imagined audiences. In relation to blogs, for example, Baumer et al.[35] problematise binary categories that define creation of the classic personal web page, such as author and reader, because 'readers', through comments and questions, shape the content and presentation of blogs. Online personal narratives, including health narratives, more than ever reflect processes of co-production and co-enunciation. Narratives also become more fragmented through the inter-textuality and imagery of blog posts, the potential lack of sequential or thematic relationships between posts and the speed of exchange. Yet, as Leggatt-Cook and Chamberlain show, narratives nonetheless reflect certain accountability to a largely unseen and vaguely-defined audience.[36]

With online communities, social networking sites and media sharing sites, the relationship between narrative, the web, interaction with multiple audiences and related processes of co-production, continues to develop and change. Interactivity is increasing, the line between producers and users is further blurred, and representations of the self increasingly include symbols, image and video, potentially distributed on different interconnected platforms. This intersection of information spaces also increasingly blurs the boundaries between healthcare delivery, self-care, self-tracking, corporate wellness programs, health education, consumer marketing, etc.[37] This 'publicness'[38] about individual health status reflects the convergence between two growing social trends: (a) self monitoring one's health status[39] and (b) participating in the 'confession society',[40] whereby individuals are encouraged to put as much of their lives online as possible.[41] This not only has bearing on what and how people learn about their own and others' health but also opens individuals to various forms of (third party) surveillance and intervention in their personal health practices.

Lupton has argued further argued that various parties can capitalise on individuals' personal experiences.[1] According to Lupton, two discursive ideals meet through online platforms that encourage patients to share their experiences. She argues that a new form of patient assemblage (the digitally engaged patient) works together with a new form of data assemblage (the digitised patient experience) to enact an emergent digital patient experience economy. As part of this economy, socio-political discourses reflect more emphasis on patient participation, crowdsourcing and—most important for the purposes of this article—collaborative relationships between patients/lay persons and healthcare professionals and providers for sharing data on medical or health-related topics. Hereby, according to Lupton, patients' online accounts of their medical conditions and experiences with healthcare institutions become valued not only for the support they offer to other patients, but also for the increasing commercial value they have for other parties.[1]

With respect to personal experiences shared via social media, discourses of health and illness have been examined in videos produced by individuals in private settings and posted on media sharing sites (e.g. YouTube), especially for contested health topics.[42–44] Narratives such as those examined by Harris et al. express an ambiguous state between health and disease, between normalcy and pathology. As Harris et al. argue, it is necessary to look not just at the story, but also at the sociality of storytelling: the material conditions that influence text development,

practices of editing and shaping performativity, the different platforms and mediums used or referred to, and other narratives from which words, ideas and plots are drawn—all of which shape the stories being told.[44] Resonating with the argument made by Hine almost a decade earlier, Harris et al. follow Gubrium and Holstein[45] in examining the relationship between what is being told (new actively-constructed states of health/illness ambiguity) and how (new platforms for creating narrative and new forms of public engagement).

Technology-specific characteristics of microblogs contribute to shaping specific forms of health narrative. The context of the story's production—including the technical mediation of the account—creates conditions of storytelling that influence the narrative on multiple levels. Twitter-specific conventions such as re-tweeting may add to the ambiguity of the story and can be understood in diverse ways: a form of information diffusion, amplification of specific ideas and a means to participate in an otherwise diffuse conversation.[5] Analysing @replies and hashtags (#) helps identify the central users, activities or topics and how these symbols are used as coordinating mechanisms in conversations.[2,13]

The literature on online health narrative seems to concur that the stories being told simultaneously constitute both a *public record of past selves* and an *ongoing redevelopment of the current and future self*. This is especially evident in the case of Twitter. Being premised on the idea of the momentary status update (what's happening/how are you feeling *right now*)[46] provides the opportunity to look at the reflective, prospective and real-time co-construction (both through specific prompts from followers and in relation to the imagined audience) of health narratives, as well as how these are intertwined with the narratives of the everyday.[47]

Methods

This study examines the aforementioned media event: the first live-tweeted heart operation in the Netherlands. While the case is exceptional and non-representative, the work of Boyd and colleagues shows that studying high-profile cases[48] and celebrity practices,[3] especially with relatively 'new' media such as Twitter, provides important lessons about use. We therefore selected this case on the premise that it enables us to tease out the intricacies of microblogged health narrative. Moreover, as is further discussed below, time is an enemy for researchers collecting tweets (see Karpf[49] on time as a methodological issue in Internet research). Choosing a high-profile case enabled retrieving posts that may have otherwise become lost in everyday information exchange.

Data collection

With so many messages exchanged daily, messages disappear rapidly and may become hard to trace. While there have been significant developments in software that mines Twitter in *real time*, at the time of data collection, there were few tools publicly available for mining archived tweets. Twitter prohibits screen scraping technologies that serve such a function and we did not have access to data from commercial resellers of Twitter firehose data, whereby we missed flow and metadata. Nearly one year after this event, Twitter began offering users personal archives, however this was not available for non-English tweets at that time. For this project we took screen shots of various points in time and manually copied and pasted the tweets to an Excel file, where we structured and coded the data.

We gathered tweets posted between 4 December 2011 (the day of the first tweet) and 4 March 2012 (four months from the initial start date and five weeks after the operation) from the patient's Twitter feed. This was the height of activity on the feed and approximately the period that the hospital monitored and tweeted with the patient. We divided the tweets temporally: pre-operative phase (4 December 2011–25 January 2012; $n = 721$ tweets), operation and recovery (26–28 January 2012; $n = 309$ tweets) and post-operative phase (28 January 28–4 March 2012; $n = 522$ tweets). We initially captured 1552 tweets; 4% were 'private' (i.e. blocked from view to followers; a tweet was evident but the content was hidden). These private/blocked tweets were necessarily excluded from the final data analysis. From the patient's responses we could see that these protected tweets were from three specific users.

We followed all links from the tweets to pictures, videos and texts. We searched via Google for the Twitter handles of the patient and the cardiologist. After 10 pages of Google returns, there were no unique returns and the search terms were present in fewer than half the hits on the page. This search delivered 24 additional web sources: the Cardiology department's Flickr page, the Dutch Ministry of Social Affairs and Employment's Flickr page, six YouTube videos (three snippets of one consultation between the patient and cardiologist, one promotional film for the event and two media interviews with the patient), the patient's Facebook page, one Storify page, two slide-sharing sites (containing presentations from the hospital), four medical news sites, four self-identified 'cross-media' platforms that aggregate social media-related news, three general news outlets and one English-language blog. Since we only had permission to collect the tweets posted on the patient's profile, there was risk of a one-sided view; we were only privy to 'half' of the conversation (only the patient's tweets,

re-tweets and replies to another poster). However, given the purpose of this research (to examine the development of individual patient narrative), the tweets and re-tweets from the patient's feed provided ample data for analysis.

Throughout the project, we were sensitive to discussions regarding the appropriateness of social scientists capitalising on 'public' information on the web.[50,51] Considering the sensitivity of the healthcare context and specifics of this case, especially the issue of *intent* (i.e. when consenting to the project and posting tweets, the patient and other users were unaware that the tweets would be analysed and reproduced in a scientific publication), we have opted to deviate from the standard culture of Internet studies and not use the patient's name or any actor's actual Twitter handle in this article. However, given the high-profile nature of this case and our analysis of newspaper articles and online interviews, one can arguably deduce the identity of the hospital, patient and others involved in producing this online narrative. We therefore obtained express written permission from the hospital, physician and the patient to collect and analyse Tweets and related data. Because we have already published an analysis of the ethical issues related to this case,[52] including our own roles in the process, we do not delve into ethics-related topics further here, but focus on analysing the emergent narrative.

Data analysis

The tweets were placed in three separate Excel files (one per phase) and colour-coded for single tweet, conversation and re-tweet. Inductive coding was done per phase by the authors independently and then compared: first the pre-operative phase was coded because it contained the most tweets; after reaching agreement on primary and secondary content categories, each author applied the revised set to the operation/recovery phase and then re-coded this phase for new themes. The same process was repeated for data from the post-operative phase and the additional web sources. Translation from Dutch to English was conducted by the first author (a native English speaker certified with Dutch as a second language) and checked by the second author (a native Dutch speaker).

Given the large number of tweets, we also performed a quantitative analysis by splitting words, removing punctuation marks, then counting the number of words per tweet and number of tweets per phase. The words were then aligned in a single row and a pivot table was run to determine which words were used most frequently in each phase. The results presented here are derived from the qualitative analysis, although some quantitative data is used where possible to provide extra contextual details. The tweets quoted in the results are de-identified, referred to as a category, such as 'name patient', and identities are made generic, i.e. 'handlepatient', 'handlecardiologist' or 'handlefollower'. The translation remains true to use of '@' and '#', but links to pictures or other online content have been replaced by [link].

Results

As the operation began as a media event, the narrative process also begins with the *event*, rather than the introduction of the self (and the related explanation of biographical disruption) by the patient that might be expected based on earlier analyses of health narratives. We first consider how this context for the patient's tweets (promoting the event and experimenting with Twitter) influenced the starting points and co-construction of the patient's narrative of atrial fibrillation and corrective surgery in real time. We then examine how narration by others also led to concurrent perspectives of the operation online, paying special attention to the idea of 'tweeting by proxy' evident in this case.

Promoting the event

The cardiologist who initiated the event intended to use it to educate the public, increase political attention for healthcare innovation and give health insurers a better impression of the 'patient experience'. These goals merged into a Twitter campaign cantered around an individual patient that did echo restitution narrative by encouraging the public to 'follow the patient's journey to a better heart'.

The patient's Twitter page, in keeping with health narrative, originally started with personal identifiers (age, family status and occupation) followed by the medical condition and proposed solution. Once the patient began posting tweets, however, little was said about the condition/operation, with the initial focus being on use of Twitter itself. Interestingly, the first layer of narrative in this patient's tweets is not one of 'disruption of normalcy,' as is often identified in studies of health narrative;[31,44,53] rather, it is one of promotion:

> "I was in the #namehospital to make pictures for my site and Twitter account. #handlepatient #handlecardiologist" (4 December)
> "The hospital where I will be operated. #handlepatient #namehospital #Twitpic" (with link to picture) (6 December)

Especially in the pre-operative phase, the patient promoted not only the event and the hospital, but also the cardiologist, operative team and an industry partner

that had provided technology specifically for the event. Patient peers were especially encouraged to pose their questions: 'Fellow patients, sound your voice and ask your questions' (10 January);

> "Feel free to send questions to @handlecardiologist @handlehospital or @handleindustry. They'll do everything in their power to answer all questions asap. #handlepatient" (12 January)

The hospital and industry partner assisted in this promotion. The medical journalist who helped conceive and develop the event was from the industry partner and tweeted daily requests for status updates, while the operative nurse posted pictures of the views of and from the operating room with tweets, 'this is where we'll treat you' and 'this will be your view next week' (8 January). One of the cardiologists referred to the operating room as 'your room' and emphasised the recent addition of the most advanced technology. According to the primary cardiologist (interview June 2012) the cardiac team and staff members contributed to the dialogue and encouraged the patient to provide information. Engaging with caregivers on this platform evidently impelled the patient to respond:

> "@handlenurse I've now seen the rooms. The modern technology eases the mind. #handlepatient" (January 8)

In one of the video interviews, the patient explains that the frequency of the tweets was initially agreed upon at three per day (status updates in the morning, afternoon and evening). These early tweets helped the patient provide information until the practice of tweeting became familiar (and long surpassed three per day). This points to the co-construction of narrative about the process and structure around the operation, including the social conditions whereby the patient is encouraged not only to answer questions such as, 'How are you feeling?' but is made complicit in emphasising the positive aspects of the hospital and confirming that technology is up to date. The tweet also adds an emotional dimension of comfort with the statement that it 'eases the mind'.

Experimenting with Twitter and 'going live'

Due to the experimental nature of the media event, the patient was online and tweeting with the hospital, promoting the event *prior* to the official date for following the feed. Although there is a chronological order to most of the tweets that enables tracing the narrative through time, we also see that the conditions of the media event lead to several *different* starting points for the narrative (both temporally and technically/

spatially) as those involved with the official event experiment with Twitter and then officially 'go live' with the first explicitly performative act of the promotional narrative. Thereby, it is in January that the patient re-initiates the narrative:

> 'Today officially live as @handlepatient. Starting now I can be followed live via twitter. If you have a question tweet me, just do it! #handlepatient' (9 January)

From this point, until the day of the surgery, the patient posted a regular countdown to the event: 'Starting today people can follow me another 17 days until the operation. #handlepatient'.

This temporal multiplicity was evident when the cardiologist corrected the researchers' reproduction of the sequence of events in drafts of other articles written on this topic. Whereas we dated the first tweet as December 2011 (test tweet), the cardiologist regularly changed this to January 2012 (official 'live' tweet). Each starting point in the online narrative therefore serves a slightly different purpose in calling attention to the pending operation. There are additional starting points as the event is posted to other websites (such as Flickr and Facebook) and promoted in newspaper reports and television interviews, revealing the non-linear nature of the narrative.

After the introductions, the pre-operative phase is punctuated with reminders from the patient to the public to send questions and with requests from Dutch journalists for interviews, showing how the narrative is simultaneously unfolding the patient's story and promoting the day of the event. In the next section, we examine how the narrative further unfolds through these various online and offline interactions.

Co-constructing narrative in real time

According to data from one of the aggregate sites, at the height of the event, 75% of the patient's tweets were *reactions*; at the time of writing, this was approximately 45%. In this section, we examine the 'who and what' of the co-constructive process: which (types of) followers are visible, what role they play, and the categories of tweets that evoke responses from the patient.

During the pre-operative phase, 80 individual twitter users interacted with the patient via Twitter; this number dropped to 43 during the operative phase and increased to 52 in the immediate post-operative phase. Some of the obvious co-constructors, mentioned above, are hospital staff members, the industry partner represented by the medical journalist and other interested journalists. Further, there are those who self-identify as patient peers ('I also had this operation' or 'My doctor thinks I might need this operation'), friends,

family and the generally interested/curious, including those who explicitly indicate joining Twitter just to follow the operation or contact the patient.

There are four recurring themes in the tweets: (a) new challenges to professionalism; (b) mutual exchanges of information, support and advice; (c) increasingly personal (and public) details; and (d) questions about 'resuming normalcy'.

Challenging professionalism. Hardey's study of online narrative shows how patients not only present their stories, but sometimes challenge or question the professional.[31] Interestingly, in this case, the patient demonstrated an unwavering trust and confidence in the knowledge and handling of the hospital, cardiologist and the team. This was evidenced in statements such as 'From Boston looks like I'm in good hands in @namehospital, but I never doubted that' (January 13) or (in assessing the operation) '@follower it went incredibly fast [namecardiologist] knew exactly what he had to do' (January 27), as well as in referrals to the doctor's Twitter feed and the possibility to ask questions and receive answers.

Although the patient does not challenge the physician's medical expertise, others question the actions taken by the hospital and the doctor.

> What will the next hospital do to be modern? (Letter to the Editor, local newspaper, February 2012)
> I sent @cardiologist an email yesterday. Will he respond by email? Tweet is not appropriate (12 January)

While the letter to the editor implicitly critiques the institution's motives, the tweet is more explicit in the opinion that a pubic answer (and perhaps such a curt answer as contained in a tweet) is not befitting of personal questions. This focus on the process of information exchange shifts attention away from the patient's personal narrative and introduces larger questions currently facing actors in healthcare, regarding both the appropriateness of using social media for doctor-patient interaction and the ethical consequences of increasing 'market push' in healthcare that influences how institutions promote themselves to patients.[52]

Coincidentally, this series of tweets is interwoven with the physician's tweets (re-tweeted by the patient) from a professional conference, which reiterate that the professional's own medical knowledge is up to date/ state of the art: 'news from Boston: more insight why overweight and sleep apnoea (breathing pauses at night) can cause bosom fibrillation' (12 January). Professionalism in one area (communication with patients) is being questioned while professionalism in another area (medical knowledge) is simultaneously being reaffirmed.

Exchanging information, support and advice. Especially in the pre-operative and post-operative phases, the patient not only provides personal status updates, but also uses these moments to *gather* health-related information from patient peers. The patient's own experiences and experiences of followers comprised 9% and 9% of the tweets in the pre-operative phase and 14% and 10% of the tweets in the post-operative phase, respectively. In these mutual exchanges of information, support and advice, the patient's narrative takes on two roles: (a) encouraging others to post their experiences or questions (information gathering) and (b) providing moral support regarding pending or past surgery. Sometimes these supportive tweets are as simple as 'hang in there', at other moments they may be in the form of sharing concerns and/or asking questions preceding the operation.

When gathering information, the patient tended to ask peers individually which medications they used, how long their procedure lasted and if they felt immediate effects. Through these questions, followers now gain a sense of the health condition as a 'disruption of normalcy', as the patient repeatedly asked peers how long they had symptoms, if one operation was enough (or if symptoms returned) and how long after the operation they had to wait before returning to work, walking, cycling, etc.

The patients and peer-followers exchanged information about why their physician chose one medication over another, dosage and effectiveness of medications and experiences with operations in other hospitals. They discussed (shared) symptoms, such as tightness in the chest, and exchanged tips and advice about how to deal with these. There were also tips for the operation.

> @handlepatient good luck with the countdown. Be sure to visit the toilet ahead of time. After the operation you must lay flat at least 4 hours, had ablation 9 december (16 January).
> @handlepatient heard that the operation is tomorrow. FREEDOM. Advice: try to relax (26 January).

The patient was not alone in providing and requesting information, but also made active use of the doctor's Twitter presence by forwarding questions, in cases where the patient was unable to answer these directly or wanted to double-check the answer.

> @handlecardiologist is it local or general anaesthesia? (multiple tweets)

Moreover, the operative nurse would weigh in on advice:

> @handlepatient, Hi [patient], just a couple of days and then we'll help you get rid of your AF, do you have your warm socks ready? (23 January)

These exchanges show how the individual Twitter feed simultaneously serves its educative purpose by becoming a conduit of information exchange about the condition and the operation. Followers eventually directed their questions to both the patient *and* the medical team. Interestingly, although the hospital monitored the Twitter feeds, the medical team only responded to questions directly sent to their Twitter accounts. They did not intervene in patient-peer conversations where patients shared advice, unless specific questions were forwarded by the patient or a follower.

Increasingly personal—and public. As the operation neared, the narrative shifted from broadcast posts (general exchanges between multiple followers) to specific last-minute instructions between the doctor, members of the hospital staff and the patient. This part of the narrative, which (historically speaking) would typically remain in the protected consultation space between the professional and the patient, become *open to the public*.

> Final check before the ablation #handlepatient: everything okay, blood thinners, kidney function, 3 not 2 right pulmonary veins! But that's not a problem (18 January).
> @handlepatient just to be sure DON'T stop taking the blood thinners. Keep going as usual (22 January).

This 'opening out' of the consultation via Twitter was criticised in the aforementioned letter to the editor of the local newspaper: 'Suddenly, healthcare is no longer a confidential [exchange] between the doctor and patient' (February 2012). Once again, the patient's individual narrative becomes intertwined with a metanarrative on the issue of appropriateness of using the medium for professional-patient communication in the healthcare setting.

Another opening out of personal experience takes place closer to the operation, when the patient begins to include more elements from home. Whereas there had been incidental mention of personal interests earlier, these were generally phrased in a medical time frame (how long after surgery until I can walk my dogs, have a beer, etc.) or punctuated with humour (great first half of the [soccer] game, good for my heart!). But closer to the operation, the patient shares the emotional weight that the pending operation is having on family by relating moments such as lack of sleep because of a child's nightmare and posting a one of the children's drawings of a new heart. This reveals the impact not just on the patient, but also the family, whose emotions are now shared not only with one another but also the multitude of online followers.

Resuming normalcy. In contrast, in the postoperative phase, the narrative moves away from the event, increasingly focusing on daily activities and the process of 'resuming normalcy'. Tweets rarely referred to the heart condition or operation. Rather, they were about 'everyday life' in the form of the topics that were interwoven in the earlier narrative: walking the dogs, enjoying soccer, and family life. Follow-up interviews with the patient led to statements that the amount of time spent tweeting was also significantly reduced. Currently, the introduction on the patient's Twitter profile has been modified to a retrospective statement, 'I *was* an atrial fibrillation patient, but *was successfully treated* at (name hospital).' Hereby the online identity is that of a heart patient, but suggests a new/different health state, reflecting indeed the idea of restitution. And while the patient's personal tweets are no longer care related, the tweeter feed still contains the identity of a patient and this introduction still promotes the hospital to potential new followers.

Narration by others

In addition to co-construction through fielding or forwarding questions, re-tweeting, etc. there were at least three identifiable instances where this story was (partially) narrated by others. The first instance was when *web users* reproduced parts of the story on sites such as 'Storify', which suggests a co-creative process of story production. Although this particular reproduction did not add anything new in the telling (other than commenting on an 'operation in 140 characters'), it potentially added audience members, influencing the reach of the story. This 'storification' was largely attributable to the fact that this was a primer in the Netherlands —thus it was 'storify worthy' because it was unique. This attests and contributes once again to the larger narrative about incorporating social media in healthcare that encapsulates the individual patient's narrative about dealing with a specific heart condition.

A second instance was when the *patient's family* assumed the role of Tweeting 'On behalf of @handlepatient...' (26 January) during operation and recovery. This began when the patient announced a break in tweeting in order to visit with family members prior to the operation. When the tweets resumed during (and immediately after) the operation, it was the patient's account and ostensibly still the patient's voice that was speaking (explicitly written and posted 'on

behalf of' the patient), but still physically done by someone else: '@follower lots of support from my [spouse] who takes over the tweeting and I just have to say what to type' (21 January 2012); 'My [spouse] and the doctors will both be tweeting during the operation' (22 January 2012).

A third related instance is both partial narration of the patient's story and development of a new story that temporally coincides with the patient's story. When *technicians posted pictures* of the procedure to Twitter and Flickr, they shared the patient's narrative of undergoing an operation. But at the same time, their narrative version introduced three new perspectives: the *professional* perspective, the *outside observer* perspective and the *institutional* perspective. Through the pictures, followers were simultaneously given the doctor's view on the operation and a view of the doctor doing the operation, from the perspective not of the patient, but of someone 'outside looking in'. However, these are neither random moments in the story nor the spontaneous status update ('what's happening?') that typically characterises microblogging. Rather, the photo moments had been pre-selected, with a carefully crafted script of captions to accompany the pictures that were to be posted. This separated the technical aspects of the surgical process from any comments regarding the actual condition of the patient—for obvious legal and ethical reasons[52] — and introduced followers to *educational* messages about specific themes related to the operation, such as hygiene.

> "Sterility during the procedure is very important. Hands are always washed properly." (Picture caption)

With the pre-determined messages, the hospital also answered real-time questions from followers regarding the procedure:

> "3D model is positioned over the live x-ray in order to steer the catheters as precisely as possible" (Picture caption)
> "@handledoctor I was just going to ask what the 3d model is for. Interesting and educative." (Response to picture)
> "@follower the left bosom is complicated 3D anatomy, placing scars is precision work." (Response to question)

Showing pictures also gave the outside observer a view of the technology used during the procedure and promoted the industry partner's role in providing large screens to increase visibility for the technicians and surgeons.

> 3D reconstr. with [name partner and name technology] placed over live x-ray. Right catheter in the pulmonary veins #handlepatient [link to picture].

#[partner] made an XL screen for this type of procedure giving the cardiologist an overview in one glance. #handlepatient [link to picture]

The narrative of these tweets is arguably part of a public pedagogy[40] intended to inform a larger population about the heart and cardiac operative techniques, as well as more general health themes, such as hygiene. It is also a promotional vehicle for the hospital and its industry partner in this event. The pictorial with commentary is a new entity that stands alone on Flickr, yet simultaneously remains interwoven with the patient story on which it is based and the Twitter feed through which that story is primarily told. Told from this perspective and combined with pictures of the patient being led to and from the operation, the text and images present a friendly, responsible and patient-centred hospital with state-of-the-art medical technology.

These instances of explicit narration by others and the links between Twitter and Flickr reveals aspects of social media narrative that are in need of further exploration, due to the interesting development that at certain moments during the operation both the physician and patient were 'tweeting'—by proxy—temporal complements of the event, reflecting not only different perspectives, but also different ways of telling a shared narrative.

Discussion

In this article we examined the content and process of how an individual patient narrative was co-constructed in real time via Twitter and other media. This narrative follows a similar process to that identified by Nettleton and Hardey[26] in first setting the scene and promoting the characters, before pointing to the solution. Similar to the case examined by Nettleton and Hardey, these institutional steps adhere closely to the restitution narrative and the patient's narrative is a combination of biographical disruption, restitution and quest. At least three of the four categories of online narrative identified by Hardey[31] on the basis of personal home pages are still evident, despite the progressive transition to a different interface with its own unique rules, syntax, etc. The categories 'explanation', 'advice' and 'solution' (albeit, not in this particular sequence) were represented in the tweets that were exchanged between the patient and Twitter followers. The final shift toward specific products may not be a logical one in this particular case, but could appear elsewhere in the future.

Such similarity leads us to question the novelty of this case — whether and how it differs from earlier studies of (online) patient narrative. After all, the co-construction of health narrative is well-recognised. While research has specifically focused on the role of

physicians or other health professionals in co-constructing patient narratives, it is also fairly common for patients to respond to the question, 'How are you?' and in the process relate a narrative of health/illness or well-being to others. Social interactions where individuals are asked how they feel, how treatment is progressing, etc., contribute to real-time, perpetual narrative co-creation, reflexivity and the assessment of the here and now — whereby answers in one instance may reflect realisations from earlier conversations, partially obscuring co-construction. Even the idea of forward-looking ('anticipatory') health narrative has been noted.[54] Moreover, stories are reproduced by others, for others. People may relate stories they have heard, even about someone they may not know directly. Physicians and other medical practitioners often reframe patient stories or images for health promotion, medical education, academic conferences or case reviews. And, of course, social scientists reproduce narratives in their own work. If narratives are, arguably, already perpetual/continual, co-created, distributed and retold, then where is the novelty in this case?

We argue that the novelty lies in the *broadening arena* of actors involved in co-constructing this narrative and the *visible connectivity* of (and ability of an interested follower to jump between) temporally and spatially concurrent narratives of the same story. At the time of the event, headlines and storified pages referred to 'an operation in 140 characters', significantly limiting the interpretation to a focus on technological characteristics, whereby tweets were seen as *isolated* entities, rather than a *body* of communicative utterances. Examining the interplay between context, content, process and technical aspects reveals how the narrative expands in time, reach, contributors and media/technical interfaces used. The connections between previously dispersed components become visible,[55] whereby the complex interplay between different interests also comes to the fore.[1,39]

Early on, hospital staff and the medical journalist interacted with the patient in tandem to provide momentum in involving both the patient and the public and to generate interest in the event. These interactions also served to promote medical products and services. The institutional view discussed above is thus not only about *public pedagogy* for communicating health-related information (in this case, to teach the public about the heart) as mentioned above, but also about *marketing*,[1,52] i.e. informing the public about the hospital's operative options and the new medical technologies that would be used during this specific operation. This shows how the micro-level narrative of the patient's health-related concerns and daily activities that somewhat 'messily' evolves through answering follower questions becomes interwoven with — and simultaneously *partially obscured by* — the meta-narrative of the 'event' and its multiple 'offshoot' narratives, including the concurrent, 'cleaner' pre-programmed texts that provide the professional, institutional and outside-observer perspectives.

Social benefits (of public support) for the patient are coupled with potential financial benefits (name recognition, growth) for the institution, making this case another example of what Lupton calls the digital patient experience economy.[1] With the aforementioned convergence between personal health monitoring and the 'confession society', social media are increasingly used to encourage patients to self-report their health or genetic data,[51] share illness experiences in online peer discussion groups,[56] rate/review professionals and institutions[57] and, now, to tweet about their health. Whereas the potential benefits of such sharing are widely proclaimed in academia,[38,58,59] sites that encourage patients to do so have also been critiqued as attempting to co-opt, commodify or otherwise capitalise on patient (self-tracking) data, opinions and experiences.[1,56] Although these platforms represent both patients and doctors as generators and beneficiaries of data exchange and thus mutually dependent on one another,[1] as others have also shown, discourses of sharing personal experiences become interwoven with discourses of good citizenship.[26,60] Although the specific claims vary depending on the platform in question, various websites encourage patients to share their personal stories using the argument that one person's contribution ostensibly benefits not only other patients, but also health systems, policymakers and/or science in general.[57] These platforms focused on lay/patient information-sharing depict participation as simple, quick, and simultaneously optional and obligatory.[57,60]

This case indeed contains a comparable meta-narrative of helping others and improving care, noticeable in the physician's goals to teach the public about options for resolving heart conditions, show insurers patients' daily struggles and give politicians insight in the potential benefit of new technologies as well as in the patient's reasons for participating. The hospital first encourages the public to participate by 'following the journey', but this encouragement is later taken over by the patient who asks questions of peers who have the same condition and also encourages the general public to ask questions. In contrast to the cases mentioned in the preceding paragraphs, the discourse of disclosing information does not come from a third-party platform established for the purpose of driving information exchange; rather, this discourse comes directly from the patient, acting as a vehicle for the media event. Tweets that encourage others to divulge information or post questions lean both toward the optional ('if you have a question') and the obligatory ('just do it!').

As such, the disclosure practices of both the patient *and* the followers are what Lupton — in discussing self-tracking — refers to as 'pushed' (the initial incentive comes from another actor or agency), and possibly even 'exploited' (information is repurposed by said actors for the benefit of others).[39] Followers and offline observers also recognised this, explicitly questioning the appropriateness of the medium for parts of the health information exchange, and the motives of the institution. Moreover, several individuals protected their tweets, with only the patient's replies revealing glimpses of these conversations, or removed the interaction from Twitter completely by requesting telephone or email contact. This may indicate varying levels of (dis-)comfort with using such a public interface to discuss personal health topics (whether for oneself or another) or could be a direct result of the magnified publicity of this case by nature of it being a created media event. Individuals may have had various reasons for resisting disclosure by not publicising certain interactions. Nonetheless, the hesitation on the part of some (and the questions raised by others) indicates that not all individuals are as open to using social media for exchanging health information as was the patient in this case, indicating the continued need to assess appropriateness on a per case basis.[52]

Despite the increased visibility of many aspects of this case, some elements were less prominent than initially expected. Reposted narrative tended merely to repeat what was already there, whereas re-telling might have added nuance, emphasis, commentary, questions, etc. Because no one commented on the Flickr photos (comments were possibly turned off), the pictorial remained an institutional performance that was 'co-constructed' only in relation to an imagined audience, rather than through explicit contributions from actual followers. Given the predominant discursive emphasis on crowd-sourcing and commentary as aspects that differentiate social media from other online and offline interfaces, this lack of response is notable. Specifically in relation to the unique syntax of tweets, hashtags also had a reduced role in this narrative. The posted tweets were mostly tagged with the Twitter handles of the patient and physician), almost as a signature to the text of the tweet. Additionally, few followers tagged their content. The hashtags led to other tweets related to the event, but did not contribute to sorting the content thematically.

Kivits indicates the importance of continuing to examine how online spaces contribute to health-related knowledge and understanding.[47] Future studies of microblogging in relation to health narrative should consider how technical aspects help users to co-create emphasis and connect on the basis of shared interests/concerns. Studying hashtags (and retweets) may reveal how Twitter users categorise their content, what aspects they highlight and which comments or questions are deemed worth repeating and by whom.[13] Studying the accompanying social processes may also reveal how interest in a given narrative process changes through time — for example, when patients or professionals may be led to tweet by proxy or when and why users choose to follow (or un-follow) one another.[61] Moreover, studies can examine how different types of users make sense of the multiple (types) of narratives, distributed across platforms and media, that become intertwined — whether they understand the interplay of interests and whose knowledge or health understanding ultimately prevails.

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