Cancer Narratives on Social Media as ‘Small Stories’

An investigation of positioning, supportive (dis)alignment and tellability crises in cancer storytelling on Instagram

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Cancer narratives shared on social media platforms have received increased academic interest over the last decade but often without sufficiently acknowledging the media specific narrative affordances of these platforms. The article will address this problem, by first presenting a ‘small stories’ approach to studying illness narrative on social media and then putting the approach to work in a case study of a Danish cancer patient’s Instagram profile (@jannelivsnyder66). The paper argues, that the storytelling practices on the profile can be analytically approached by focusing on the interplay between three co-constitutive levels of interaction: 1) a level of the desired illness narrative and position that the narrator, influenced by available cultural discourses and interaction with followers, hopes to be able to tell; 2) a level of sharing everyday posts, which can either support or disturb the desired narrative; 3) a level of follower responses, where relations between the desired narrative and singular posts are monitored through processes of liking and commenting. Followers
of social media cancer narratives should in light of this not be understood as an audience witnessing an individual telling his/her “own” story, but rather as crucial contributors to the social interaction and co-creation of desired narratives, subject positions, narrative progress and tellability. In conclusion, the article thus stresses that cancer storytelling on social media, despite the strong biological connection of the disease to an individual body, emerges through inherently social processes of reading, liking, commenting, monitoring and co-deciding narrative practices.

Introduction

Social media is a new important platform for (semi)public narrations of illness, and cancer narratives shared on social media platforms; such as blogs, Facebook, Instagram and YouTube (Kaplan & Haenlein, 2010; Klastrup, 2016) have in particular received increased academic interest over the last decade (Andersson, 2017; Coll-Planas & Visa, 2016; Heilferty, 2018; Nesby & Salamonsen, 2016; Orgad, 2005; Pitts, 2004). However, I would like to argue that analytical approaches to this type of narrative material are still largely modelled on typologies and definitions developed in literary studies aimed at understanding book-based illness narratives (Frank, 1995; Hawkins, 1999; Jurecic, 2012). With a few exceptions (McCosker, 2013; Page, 2012; Stage, 2017), social media cancer narratives are treated as though they were books, that is, as fossilized textual entities characterized by a particular narrative structuration of past events and with a single dominant narrator communicating his or her individual story to a passive audience of receivers. This implies, that the dynamic ‘living’ (Ochs & Capps, 2002) and interactional aspects of narrating cancer on social media are repeatedly downplayed – or at least not sufficiently integrated into the methodologies developed to approach this type of storytelling activity.

The aim of this article, is to present a ‘small stories’ approach (Bamberg & Georgakopoulou, 2008) to studying illness narrative, in order to better acknowledge social media as a dynamic and interactional storytelling platform. The small stories tradition has thus far not played a prominent role in studying illness narratives but I argue that it is becoming increasingly relevant as more and more illness experiences are shared and developed on social media. This approach is not solely relevant for understanding cancer storytelling on social media but can be used in any exploration of illness experiences narrated through the temporal and interactional affordances of social media. For that reason, this article primarily contri-
butes to research interested in the media-specific characteristics of social media illness narratives and secondarily to the specific strand of narrative research dealing with cancer experiences.

In the article, I will apply the ‘small stories’ theoretical approach to the communication taking place on a female cancer patient’s Instagram profile: @jannelivsnyder66 made by Janne Hinrichsens (born 1966) (2880 followers, 2216 following). My empirical material will comprise the 403 posts shared between November 2015 (when the profile was established) and June 2018 (when the empirical material was collected). I selected this case study because Janne highlights and directly addresses some of the often more hidden interactional logics that characterize social media cancer narratives. This specific case is clearly too empirically limited to offer generalizations to understand a wider population of cancer patients, but it will hopefully provide preliminary theses about the narrative and interactional dynamics of sharing cancer experiences on social media and thus will hopefully contribute new knowledge to the budding field of social media illness narratives.

When analyzing and coding the posts on @jannelivsnyder66, I was particularly interested in important differences in how Janne positions herself over time and how Janne interacts with followers. To establish an overview of types of communicative content and sharing practices, and changes during the lifespan of the profile, I began coding the material through an explorative process of categorizing the 403 posts in relation to types of content, modes of sharing, use of selfie types, and the number of comments/likes. I also took notes on the overall commenting practices of the profile. Not all the coding results are directly relevant to this article, but they all helped to reveal the narrative and interactional dynamics I address here.

In terms of ethics, the collection of empirical material is based on Janne’s informed consent, all the users who commented on the Instagram profile have been anonymized, and Janne was offered the chance to read and comment on the article before it was published (Ess & AoIR ethics working committee, 2002, 4; Markham & Buchanan, 2012, 4).

Illness narratives on social media as an interactional practice

When investigating 403 posts about a person’s illness, it is tempting to somehow ‘stabilize’ the material as an enclosed set of posts characterized by inherent tex-
tual and narrative traits instead of understanding it as having taken part in dynamic processes of interaction between interlocutors, in which, the articulation of illness can change over time and be influenced by the communicative situation. The ‘small stories’ approach is precisely an attempt to avoid this temptation and to, instead, treat social media narratives as an evolving practice that is constantly shaped and reshaped in continuous interaction about the ‘here and now’ of illness (what has happened since the last post?) and not as a coherent textual construction organizing past events.

The ‘small stories’ approach to narrative studies revises a more traditional understanding of narrative as described by Labov and Waletsky (among others). In 1967, Labov and Waletsky formulated a formal and functional definition of narrative in oral interaction, which understands narrative as linked to the articulation of non-shared personal experiences of sequential events taking place in the past (Labov & Waletsky, 1967). According to Michael Bamberg, this formalist line of thinking is contrasted by an approach in which narrative is instead understood as part of “human interactive practices” played out between interlocutors (Bamberg, 2016, 1288). The ‘small stories’ line of thinking entails also that narratives are understood as crucial for the negotiation of social positions and identities. Such a line of thinking stresses that we use narratives to ‘position’ ourselves in relation to others and in various forms of communities and thus to make “sense of who we are” (Bamberg, 2016, 1294). Through this analytical focus, ‘small stories’ are treated “as a window into the micro-genetic processes of identities as ‘in-the-making’ or ‘coming-into-being’” (Bamberg & Georgakopoulou, 2008, 379).

Practice, the self and interaction are in other words at the core of a small stories approach to narratives. According to Bamberg, such an approach must begin with the assumptions that 1) “narrative activities are embedded in previous and subsequent turns, that is, interactive before and after” (Bamberg, 2016, 1292), which invites us to focus on the role of narrative elements in the ongoing flow of interaction, and 2) “narrating activities require a great deal of interactive negotiation” (Bamberg, 2016, 1292), which implies, that we must focus on how interlocutors collaborate on creating narrative elements, in particular, communicative situations.

Other important differences between the formalist ‘narrative-as-text’ traditions and the ‘small stories’ approach are: 1) Temporal orientation: narrative-as-text traditions prioritize past events, while the ‘small stories’ approach directs us towards the sharing of “breaking news” (Georgakopoulou, 2006, 126), the “moment” or “recent” (‘this morning’, ‘last night’) or still-unfolding events” (Bamberg and Georgakopoulou, 2008, 381). 2) Tellership: narrative-as-text traditions often focus on
one teller, while ‘small stories’ are understood as co-constructed by interlocutors in everyday settings (e.g. on social media). 3) *Tellability*: narrative-as-text traditions prioritize the representation of extraordinary experiences, while the ‘small stories’ approach is equally interested in “*seemingly uninteresting tidbits*” (Bamberg and Georgakopoulou, 2008, 381), everyday occurrences, “*shared (known) events, but also allusions to tellings, deferrals of tellings, and refusals to tell*” (Georgakopoulou, 2006, 123). This implies that ‘tellability’, evaluating when a particular occurrence is worth telling, is not only a quality that a certain event/story has but is also a quality negotiated collectively in the interactive situation.

**Illness, social media and small stories**

A large amount of valuable research has been conducted on personal illness narratives in the narrative-as-text tradition, which has, among other things, focused on different genres of illness narratives in books (Charon, 2006; Couser, 2016; Frank, 1995; Hawkins, 1999) and the role of various types of metaphors within these narratives (Hawkins, 1999; Sontag, 1991). Research on illness narratives on social media that explicitly transgress the formalist or textualist model is rare. Exceptions are Shani Orgad’s investigation of cancer storytelling online (Orgad, 2005, 39) or the work of Ruth Page, who, with respect to her analysis of illness blogs, elaborates on some of the characteristics of social media illness narratives:

“(…) the stories that narrators tell about their experiences of illness are not told retrospectively from the point of recovery, but as updates that appear discontinuously as the narrator documents their experiences while diagnosis and treatment unfold. Sometimes the sequence of blog posts stops altogether without warning, perhaps for the distressing reason that the narrator is too ill to continue to write, or has even died. Within the episodic archives or social media posts, there may be little causal connection between one entry and the next” (Page, 2012, 10).

Although, this kind of academic interest in the dynamism of illness narratives on social media is uncommon it is still possible to find useful research on the more general characteristics of social media storytelling as small stories, which can also be used to analyze accounts of illness. Most significantly, Alexandra Georgakopoulou has shown how social media sites are prominent cultural sites for small storytelling (Georgakopoulou, 2016c, 268). Stories shared on social media are thus often characterized by multiple authorship, open-endedness, and a desire to cap-
ture the moment through narrative fragments. These small stories characteristics are supported by the affordances of many social media platforms that encourage the small-scale sharing of current experiences, moments, emotions, opinions and geographical embeddedness.

Switching from small story posting to small story response, Georgakopoulou has identified two different modes of positive story recipiency (Georgakopoulou, 2016b, 308) through followers commenting on the post. The first is ‘ritual appreciation’, which is a short recognition often used in relation to selfies (Georgakopoulou, 2016b), that “involves positive assessments of the post and/or poster” (Georgakopoulou, 2016b, 301). Ritual appreciation thus “serves as the visual counterpart of lots of people clapping and cheering at the same time” (Georgakopoulou, 2016b, 310). The second is ‘knowing participation’, which involves commenters adding knowledge about the post’s backstory (Georgakopoulou, 2016a, 197) or hinting at offline relationships. These responses can be seen as different types of ‘alignment’ through which “speakers signal, linguistically, paralinguistically and in embodied ways, their understanding of their interlocutors’ positions” (Georgakopoulou, 2016a, 179). Followers can of course also choose to disalign from the post by opposing it in various degrees with their comment, most notably through antagonistic strategies of trolling (Phillips, 2011), but also through processes of debating, contesting or dissenting (Knudsen & Stage, 2012).

A potential objection to using the ‘small stories’ approach is that it fails to address how larger storylines are also expected and produced on social media and how illness narratives, for example, often reintroduce a seemingly more centralized narrator (the patient) and dramatic occurrences (receiving treatment to survive) as material for storytelling. In this way, cancer narratives on social media sometimes seem too big and existential to be called small. This idea resonates with Mark Freeman’s defense of ‘big stories’, which maintains that we still require concepts to describe narratives that reflect on (and often look back on) larger periods of life and existence:

“Big stories are those narratives, often derived from interviews, clinical encounters, and other such interrogative venues, that entail a significant measure of reflection on either an event or experience, a significant portion of a life, or the whole of it” (Freeman, 2006, 2).

However, I would argue, that this point in some sense misses the practice orientation of the ‘small stories’ framework. Even telling ‘big stories’ about life or exi-
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stance is always a highly contextual and situated activity. ‘Big stories’ are always told by someone and to someone for some reason and they depend on interaction and feedback for their continuation, development and social effects (Bamberg, 2006). For this reason, it might be more worthwhile to ask how larger storylines about (the self during) illness are constructed and developed over time through interaction between patients and receivers. And why some cancer experiences do not develop into larger storylines as they are not responded to or interacted with by an engaged audience online? In other words, serious illness does not in itself produce a change of storytelling premises that prompts the patient to withdraw from social interaction in order to independently reflect on and articulate his or her ‘big’ illness story. Serious illness as a ‘biographical disruption’ (Bury, 1982) does not isolate the patient in terms of managing and telling illness stories. On the contrary, patients’ narratives about themselves are constantly influenced by, and curated to fit into, social interactions with relatives, friends, co-patients, medical authorities, or cancer bloggers while also taking up or renegotiating cultural discourses of illness not produced by the patient.

Furthermore, platform logics and affordances need to be considered when studying social media cancer narratives and interaction. Social media are not innocent channels where patients simply articulate their experiences. They are rather platforms with affordances that condition, prioritize and disseminate particular forms of storytelling, and there are important narrative and interactional differences between specific platforms. Instagram, the core provider of material for this article’s analysis, was launched in 2010 and bought by Facebook in 2012. Instagram is a ‘social networking site’ (SNS), just like e.g. Twitter and Facebook (boyd, 2011; Kaplan & Haenlein, 2010), and has its own characteristics and constraints. Firstly, Instagram (in contrast to e.g. Facebook and Twitter) gives prominence to visual communication (Ibrahim, 2015). The name Instagram fuses ‘instant (camera)’ and ‘telegram’ and thereby underlines the immediate production and transmission of a combination of something visual with something written (and short) as its core form of communication. The relative briefness of the narrative input is supported by the fact that the maximum length of text allowed in a post is 2,200 characters. Secondly, Instagram pushes users towards using mobile technologies, like smartphones, by making it difficult to upload pictures onto Instagram from the website, and thus from laptops. This constraint prioritizes on the move sharing of photos from mobile devices as the desired mode of communication (Marwick, 2015). The platform thus affords ‘networked photography’, which refers to “the practice of sharing photographs immediately after capture in real-
time, mobile visual communication, using, for example, instant messaging (IM) tools or social media applications” (Lobinger, 2016, 475). Thirdly, Instagram, besides linking people with established strong ties (like Facebook), prioritizes a more hierarchical fan-like relation between ‘the followed’, who produces visual input, and ‘the followers’, who takes on the role of responding to visuality through the heart/like button or comments.

Focusing on the cultural implications of using the platform of Instagram, scholars have argued that it contributes to an ‘aestheticization’ of the mundane through ‘banal imaging’ (Ibrahim, 2015). This fusion of aesthetics and everyday life, has supported the rise of a new segment of talented entrepreneurial influencers on Instagram with well-developed skills and competencies in terms of visual presentation, and productions of selfies (Abidin, 2016) – which are crucial for gaining popularity, or ‘instafame’ (Marwick, 2015), on the platform. This point stresses, that Instagram not only prioritizes a particular type of storytelling, based on visual, short and continuous narrative contributions, but also, that it is easier to navigate successfully for individuals with particular communicative and technological competences. This indirectly implies that specific patient groups (e.g. well-educated patients), illnesses (e.g. well-known and aesthetically unobtrusive ones) and illness experiences (e.g. those able to transform into appealing or spectacular selfies) are often more likely to be gain attention and traction on Instagram.

Narrative and interactional practices on @jannelivsnyder66

Janne Hinrichsen (born 1966) made her first post on the profile jannelivsnyder66 in November 2015. In June 2018, when the empirical material was sampled for analysis, the profile consisted of 403 posts. Jannelivsnyder66, which can be translated into English as Janneenjoyeroflife66, describes Janne’s everyday life but also the diagnosis and treatment of her second breast cancer experience and mastectomy. At the time of writing, Janne is in remission from cancer. In the following analysis I will argue, that the photo-text-sharing practices on the profile can be analytically approached by focusing on the interplay between three co-constitutive levels of interaction: 1) the level of the desired illness narrative and position that the narrator, influenced by available cultural discourses and interaction with followers, wants to tell (a narrative often focused on progressing towards a cure and expressed in
bios or individual, more programmatic posts); 2) the level of **everyday posts that share moments** more or less directly related to illness experiences, which can either support or disturb the desired narrative; 3) the level of **follower responses (through hearts/likes and comments)**, where the alignment of the desired narrative and the individual posts are monitored through processes of liking and commenting. It is important to note that none of the three levels is stable or created outside social interaction. As such, the desired narrative does not simply express the inner thoughts of the ill person but is also co-constructed and renegotiated through day-to-day communication with interlocutors.

**Positioning and desired narrative**

Janne very explicitly describes the desired or intended narrative she wishes to convey about her illness, but she also describes the type of subject position with which she aligns herself. Her ideal narrative is clearly what Arthur Franks has described as the ‘restitution narrative’ (Frank, 1995), a narrative that moves from diagnosis to treatment to cure. but, more importantly, Janne wishes to tell the story of how this process of treatment and struggle can also be filled with joy and happiness. And her followers constantly validate that she is an extraordinarily positive, happy and funny person in their comments through ritual appreciation. In the profile bio, Janne positions herself as a positive and somewhat hedonistic person (cf. the name of the profile and the wine emoji) and, perhaps less consciously, as not overtly focused on perfection (cf. the lack of focus on typos):

![Janne's Instagram bio in June 2018](image)

This self-positioning is also expressed in individual posts where her overall existential approach to life becomes an explicit theme:

“Just took a 7.4 km chemo-walk. No pain. Head is tired, but not the body. Spirit is high. The sun is shining. Life is great. And thank you so much to all of you following me. It is just as much you who makes me wanna share something on
Instagram. I want to show how important it is to stay happy and keep believing in life. Lots of fighting spirit. Humour, happiness, a positive mind, exercise, support from family and friends are invaluable things. And once in a while, you should be allowed to be a little crazy and childish although you are 50 years old” (28/3/2017).

An important part of her self-positioning is also expressed through optimistic pictures and selfies of her bare-chested or scared body. These pictures also underline Janne’s happiness and pragmatic vitality; for example, the picture below (from 17/5/2018) is accompanied by a text that describes all the breast-related health problems that Janne has endured over the years and, therefore, how happy she is to have had a double mastectomy.

Ill. 2. “The good thing about not having breast is…”

This visual focus on scar images and selfies, and the female body living happily without breasts, gives the profile an almost activist touch. It incarnates the ideal of Audre Lorde’s classic *The Cancer Journals* (1980), in which Lorde argued in favour of women with cancer renouncing their prostheses and taking the scared, bald, asymmetrically curved or flat body into the public sphere. This line of everyday body activism is clearly supported by Janne’s followers. If we examine the 10 most-liked posts, 7 of them (marked with *) are images showing Janne as bare-chested, with one or two breasts removed, while smiling.
### Ill. 3. The 10 most-liked posts on @jannelivsnyder66

<table>
<thead>
<tr>
<th>Likes/Hearts</th>
<th>Content</th>
<th>Illness phase</th>
</tr>
</thead>
<tbody>
<tr>
<td>1198*</td>
<td>Picture of scar from first mastectomy (18/8/2016)</td>
<td>Before (second) illness</td>
</tr>
<tr>
<td>1076*</td>
<td>Officially cured of the disease (8/7/2017)</td>
<td>After (second) illness</td>
</tr>
<tr>
<td>912</td>
<td>Last chemo treatment (30/5/2017)</td>
<td>During (second) illness</td>
</tr>
<tr>
<td>880*</td>
<td>Drinking and liking a beer (21/7/2017)</td>
<td>After (second) illness</td>
</tr>
<tr>
<td>827*</td>
<td>In a week my breast is removed and I don’t care (21/6/2017)</td>
<td>During (second) illness</td>
</tr>
<tr>
<td>695*</td>
<td>Scar after second mastectomy (29/6/2017)</td>
<td>During (second) illness</td>
</tr>
<tr>
<td>658</td>
<td>Preparing a public talk about my cancer process (4/10/2017)</td>
<td>After (second) illness</td>
</tr>
<tr>
<td>480</td>
<td>Chemo 10 out of 12 – only 2 to go (16/5/2017)</td>
<td>During (second) illness</td>
</tr>
<tr>
<td>472*</td>
<td>The history of my breasts and why I can live without them (17/5/2018)</td>
<td>After (second) illness</td>
</tr>
<tr>
<td>456*</td>
<td>Happy and bare-chested Janne under an umbrella (16/7/2017)</td>
<td>After (second) illness</td>
</tr>
</tbody>
</table>

In this way, liking seems to be particularly intense on the profile when posts express an image of the embodied self and an approach to serious illness that is aligned with the desired narrative of positivity. Through these peaks of liking, followers thus support the continuous micro-genetic co-production of Janne’s identity as happy and optimistic, even during the hardships of cancer.

The intense response to these scar images is also culturally conditioned: On the one hand, the images are visually provoking as they show the flat and bare-chested female body which is still a rare image in today’s society, but on the other hand, they resonate with a cultural reverence for cancer patients who are able to affectively transgress their illness, stay happy or perform vital actions of survival and struggle (Ahmed, 2010; Rose, 2006; Seale, 2002; Stacey, 1997). In this way, Janne’s most-liked selfies are simultaneously culturally provoking and culturally desired: They allow women to embrace the scared and non-prosthetic body, but the intensified liking also seems to support the notion that happy cancer patients should be praised and acknowledged. Furthermore, Janne’s scar selfies represent a certain ‘aestheticization’ of existential crisis that resonates with the desire for something visually spectacular, afforded by the platform logics of Instagram.
Supportive disalignment

On occasion, the smooth alignment of 1) the desired narrative and subject position, 2) the content of the shared post, and 3) follower responses through liking is disturbed. This occurs, when the shared moment in the post fails to correspond with the desired narrative of restitution and happiness. An example of this took place on May 29, 2017, which was the day before Janne’s last chemotherapy treatment. Here, the post does not focus on progress towards a cure and happiness but rather shares a sense of sadness and insecurity:

“Off day, right from the very beginning. Couldn’t wake up when I left my bed. Started freezing, madly, after breakfast as a sign of fever. I quickly took some painkillers, and the fever dropped. Just thought that it was really irritating as I was laying there feeling sorry for myself. I was supposed to be attending a Lady Walk together with my lovely friends, but regrettably, I can’t. I have slept a little, and feel a little better, but I prefer to stay in bed for the rest of the day. Hopefully, I will be ready for the last chemo, tomorrow” (29/5/2017)

This kind of post, which disturbs and, in some sense, threatens the narrative and affective self-understanding constructed previously through interaction on the profile cannot simply be liked (or given a heart) but calls for a comment. Comparing the ten posts that received the most likes and the ten posts that received the most comments, there are overlaps (4 posts). While the ‘most liked’ list primarily consists of posts that present news of progression that can be supported, the ‘most commented’ list also consists of posts that present news of progress being threatened or stalled. Below is a list of some of the comments on the post quoted above:

- I hope you get better soon. Don’t be afraid. Everything is going to be all right. God bless you. Kiss❌❌❌
- Øv øv Janne ✓tænker på dig og er sikker på du bliver helt klar til imorgen✓ (trans. “So sorry Janne. Thinking of you and I am sure that you will be completely ready for tomorrow”)
- Nuuurh sødeste pige da…. godt at de fleste dage er gode ved dig - og i morgen er det sikkert væk - så hold ud✓ (trans. “Sweetest girl! Luckily most days treat you well – and tomorrow it will be gone – so stay strong”)
- Årh, kram til dig ✓i dag er der brug for en sengedag. I morgen en ny dag 😍 (trans. “Hugs for you. Today you need to stay in bed. Tomorrow is another day”):
These comments are characterized by what I call ‘supportive disalignment’ where commenters do not align themselves with the shared negativity of post but instead try to transform the affective and narrative quality of the post by focusing on negativity as momentary – as a small bump in the road leading to a happy ending. The commenters thus insist that the post should be interpreted within a larger narrative framework of restitution and approached as a temporary digression. “Remember the story that you want to tell; stay happy and on track”, seems to be the point expressed through the comments. In this way, through supportive disalignment, commenters try to reconnect or realign Janne with the previously constructed subject position focused on progression and happiness. This underlines the idea that Janne is not simply telling her ‘own’ story but is telling a story together with her followers. And sometimes these followers actually take the lead by telling the story about Janne, as a happy and optimistic patient, to Janne if she forgets or begins to doubt it.

If posts divert from the desired narrative over a period of time, it can be argued that the poster is forced to engage in acts that reposition the overall story he or she hopes to tell in the future. This actually occurs after Janne is officially cured but realises that her ‘post-illness’ self will never be the same as her ‘pre-illness’ self. She increasingly acknowledges that her post-illness self is cognitively challenged, increasingly tired and incapable of doing the same things as before the second diagnosis. She slowly accepts that she will have to do less, and this new desired narrative gradually seeps into her posts – often through descriptions of her long-lasting ‘kemohjerne’ (trans. ‘chemo brain’). This change in the narrative also underlines how her profile is a platform for micro-genetic negotiations of constancy and change in relation to (the capacities of) the self.

Tellability crisis

Janne’s profile shows how describing a serious illness increases a story’s tellability in relation to a particular audience of other patients or followers interested in the disease. As such, once Janne is cured of cancer, a rather peculiar narrative situation is created. I refer to this situation as a ‘tellability crisis’, and it describes the moment when the drama of fighting death is replaced with descriptions of more mundane occurrences of living a normal life. Janne addresses this quite explicitly in a post:
“This morning I ran 3.7 km. Really nice. I hope that you want to help me a little bit. I am not so enthusiastic about Instagram at the moment. I can’t figure out if I should share something like a normal cured person or if I should continue with something related to breast cancer and the life I am now leading as a former breast cancer patient. What do you think?” (28/4/2018).

In the 34 comments on the post, Janne’s followers overwhelmingly encourage her to ‘be herself’ and share whatever she feels like. This post is interesting, because it indirectly acknowledges that many people only followed Janne’s profile because she was fighting a serious illness, and, now that she is cured, a fundamental relational problem arises. Her followers may ask: If we began following, you because you were fighting cancer and now you no longer have cancer, why should we still follow you?

Janne addresses this crisis of tellability by inviting her followers to co-create what should now be the logic of affective and narrative exchange on the profile. The previous collective contract, that fighting cancer is a highly tellable subject in relation to her followers, no longer seems to hold, and Janne thus engages her readers in redefining what about her life is now tellable. This example illustrates, that sharing stories of illness on social media is played out in a media space, where identity, relations and tellability are constantly redefined and negotiated through interaction, but it also shows that social media cancer profiles are often characterized by shifting ‘curves of tellability’ in relation to particular groups of audiences.

Conclusions

In this article, I have shown that Janne’s social media cancer experiences are constantly narrated in a tension between 1) a desired narrative positioning of Janne and her illness process, 2) individual posts that can either support or disturb the desired positioning and 3) comments that to a large extent can be understood as narratively and affectively monitoring the relationship between the desired narrative and the singular posts. The primary interactional role of the comments thus seems to be to encourage Janne to align each individual post with the desired narrative and to guide the posts back on track when necessary. Posts that are “on track” mostly attract ritual appreciation and likes, while disturbing posts of worsening conditions or crises attract comments that supportively disalign with the disturbance of the post in order to move the story back on track. If the desired
narrative faces continuous disruptive posts, it may have to be redefined, along with the subject position offered by the narrative (for example, Janne that has to acknowledge that she is cognitively challenged after the cancer treatment). In this way, comment responses seem to align with the post during positive times and supportively disalign with the post during crises.

Sharing the moment through social circulation, in other words, in light of past events and unknown future events (and narratives), provides the basic storytelling logic of Janne’s Instagram-profile, but serious illness and treatment related to cancer also seem to ‘traditionalize’ the profile by creating a more clearly demarcated main theme (cancer) and an expectation that the narrative will hopefully progress through linear phases that move towards restitution. This support findings from other work on existential uses of social media, such as Korina Giaxoglou’s work on mourning practices on Facebook:

“In terms of narrative form, they seemingly resemble the Facebook status updates studied by Page (2012) in their smallness and story-like fragmentary shape; and yet they are also seen to differ markedly from Facebook status updates in the clustering of their narrative dimensions towards the polished end of the narrativity continuum (Ochs & Capps, 2001), typically involving one teller and reporting events whose tellability is more or less shared and guaranteed” (Giaxoglou, 2015, 101).

But in light of the analysis presented in this chapter, three concerns can be raised in relation to the idea that this type of existential storytelling on social media is potentially more ‘polished’ or ‘traditional’: 1) The seemingly ‘polished’ storyline focused on moving from diagnosis to treatment to cure emerges more effectively if you read Janne’s profile continuously and omit the comments; it is less clear if you, as intended, follow her communication in posts and comments on a daily basis where the storyline is sometimes lost, diverted or forgotten in the flow of everyday posting. 2) Platform logics and algorithms are furthermore crucial players in terms of ‘curating’ (Fernandes, 2017) what comes visible and invisible, to whom on the platform and thus inherently disturb the idea of a large coherent storyline presented to an audience of followers as parts of the storyline might simply ‘disappear’ from the personalized feed of specific readers. 3) Lastly, Janne’s story is not only narrated by her but constantly acknowledged by and co-constructed with her followers through processes of ritual appreciation and supportive disalignment. Her followers are likewise explicitly invited to co-decide which type of
narrative content should be articulated after Janne’s cure. This interaction underlines, that the posts shared by Janne do not comprise a ‘big story’ in any traditional sense. The story’s perceived (polished) coherence simply relies on a particular form of (unlikely and unintended) reading, and the profile’s overall narrative – which might appear as ‘individually told’ when read post-to-post from beginning to end, is actually the result of daily social interactions with followers.

The case study presented in this article shows, that social media platforms are able to form publics of existential and affective support (Lagerkvist, 2017; Peters, 2015) or more critically a public focused on progress, positivity and vital patienthood (Rose, 2006; Stacey, 1997). This public of followers should not be understood as a passive audience witnessing an individual telling ‘her own story’ but rather as crucial contributors to the social interaction and co-creation of desired narratives, subject positions, narrative progress, and tellability. The platforms used are not simply channels for personal expression but also computational machines curating content in particular and often opaque ways. As such, despite the disease being biologically connected to the individual body, cancer storytelling on social media emerges through inherently social and mediated processes of reading, liking, commenting, monitoring, curating and co-deciding narrative practices.

References


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