

Multimodal Illness Narratives on Instagram

Sharing the Experience of Endometriosis

This article explores how illness is narrated on a shared activist Instagram account, where five women share their experiences of living with the chronic disease endometriosis. The day-to-day, multimodal, and collaborative nature of the account is an example of online contemporary illness narratives. Informed by discourse analysis, social semiotics, and research on *small stories*, this article analyzes the semiotic resources used for narrating, the social space of the account, and the particular discourses and identities that the narratives index. Following the narrative dimensions of Ochs and Capps, the analysis demonstrates a dynamic interplay between the different semiotic resources used to narrate about illness. The combination of images on Instagram, for instance, affords a sequential progression that moves the teller through space and place. In other cases, the images are used to contradict or strengthen the story that is told in writing. The account's construction as a shared space for raising awareness about endometriosis experiences also influences the stories that are told; tellers orient themselves both to previous and current stories on the account, and attend to the particular endometriosis experiences that are tellable on the account. In this way, the tellers demonstrate awareness of the typical endometriosis story, and position themselves as moral and knowledgeable endometriosis patients.

1. Introduction

Pain. My endometriosis is tormenting me right now. Stabbing like knives. Feels like someone is twisting my ovaries round, round, round. I never know when the stabs will come, suddenly they are just there and my legs give out.

Online storytelling has led to an increase in narrative practices, and a multitude of new ways to order our experiences. More specifically, this has made ordinary people's meaning making more visible. In a similar manner, recent developments in the way we communicate about health have made experiences of being ill available to wider audiences. Social media also has specific implications for how illness is narrated. An increased visibility of illnesses can serve as a basis for activism, and mobilize political and social awareness (cf. Stage 2017). Furthermore, the relationship between time and narration is different in online settings. As noted by Page (2012, 10), narrators tell stories, not "retrospectively from the point of recovery, but as updates that appear discontinuously as the narrator documents their experiences while diagnosis and treatment unfolds."

The aim of this article is to explore how illness is narrated on an Instagram account, where five women suffering from endometriosis tell their stories as a means of raising awareness. Here, issues of visibility, and the day-to-day nature of online settings, are both central to the stories told. The topic of endometriosis

– a chronic disease with symptoms such as pelvic pain, dysmenorrhea, dyspareunia, and infertility (Schoen Lemaire 2004) – relates to the storying of previously untold experiences. Despite its high prevalence, this disease is still surprisingly unknown, and several of the symptoms are similar to ‘normal’ aspects of female life. Often, this leads to a normalization of the pain and causes a diagnostic delay (Hudelist et al. 2012). The account is also an example of social media narratives; the analyzed illness narratives are multimodal and collaboratively accomplished, constituting a form of *co-tellership* (cf. Ochs / Capps 2001). The posters share the same space, but tell their ongoing and unfolding updates of living with endometriosis in separate textual units. This article also explores how these personal experiences are tied to larger stories and understandings of health. More specifically, the following questions guide the analysis:

- What semiotic resources are used to narrate about health and illness, and more specifically endometriosis, on the Instagram account?
- How are separate posts related to the story told on the account as a whole?
- What particular discourses and identities do the illness narratives index, and with which resources is this indexical work accomplished?

The questions address three interrelated levels, and reflect the analytic heuristic *ways of telling-sites-tellers* (Georgakopoulou 2007). That is, the study explores the semiotic choices in the stories, the social space that the stories take place in, and lastly, the people telling them, both as characters in the stories and as members of social groups and communities (Georgakopoulou 2015, 258). In this way, the article contributes to an understanding of contemporary illness narratives, and shared spaces for activism and storying endometriosis experiences. The multimodal nature of the data allows for further exploration of issues of visual narration, and the narrative potentials of different semiotic resources.

2. Narratives of Health and Illness

The pervasiveness of narrative has made it a well-researched topic over a range of disciplines, as noted by Toolan (2001, viii), “narratives are everywhere.” By telling stories, we order our experiences and construct identities (e.g. Ochs / Capps 2001; Thornborrow 2012). Illness narratives, in particular, have been described as arenas for presenting and negotiating illness (Hydén 1997, 55). Traditionally, these illness narratives have been analyzed as a part of researcher-elicited interviews, or patient records.

More recently, stories of being unwell have also moved to online settings, creating new spaces for comparing experiences (cf. Pitts 2004). In an analysis of autobiographical introductions on personal web pages of an online mental health community, Thompson (2012b), for instance, shows how the online narratives

could re-order the self in relation to the illness. In introducing themselves, narrators could also demonstrate expertise and draw on shared beliefs about illness and recovery (Thompson 2012b, 97). As Stage (2017, 53) notes, blogging about illness, more specifically cancer, can also be a means of mobilizing political action and spreading awareness, where small updates form parts of a larger story told about fighting a disease.

As for multimodal representations of health and illness, studies have shown how images have the potential to situate illness in everyday life. In a related study of the same mental health community, Thompson (2012a) demonstrates a shift in the use of visual discourse to convey mental health. While early versions of the website used images portraying bodies as distorted or sick, later versions featured so-called *stock photos*, that photographically depicted ‘everyday’ people. The genericity of such ‘normal’ visual imagery invites the viewer to an understanding of mental health problems as widespread (Thompson 2012a, 416). With regard to representations of chronic pain on social media, Gonzalez-Polledo and Tarr (2016) show how posters could make pain visible and attach it to their daily lives by posting self-portraits or depicting material aspects of living with pain. The day-to-day experiences of living with pain were also critically addressed through widely circulated memes (Gonzalez-Polledo / Tarr 2016, 1467). In these studies, however, the narrative aspects of images and writing are less developed. In this respect, the narrative perspective of this article contributes to connecting the personal experiences and the self to social and activist functions of sharing.

3. Addressing Everyday Storytelling Practices

As a concept used widely over a range of disciplines, several scholars have commented on the elusive and imprecise nature of the term ‘narrative,’ which risks losing its analytical potential when used too broadly (e.g. De Fina / Georgakopoulou 2012; Hatavara et al. 2013). Within sociolinguistics and discourse analysis, previous research has primarily centered around the structural and influential approach of Labov (1972), that emphasized elicited, past tense stories told by a single teller. Labov’s formalistic point of departure has led much narrative work to focus on self-contained, retrospective, and highly tellable accounts, reported in a sequence of events (cf. Ochs / Capps 2001, 57). By contrast, recent years’ work on *small stories* (Bamberg / Georgakopoulou 2008) represents a more inclusive approach, one that investigates how people use stories in everyday life. Small stories are characterized by being more open-ended, fluid and fragmentary, but nevertheless function as resources for creating identity and making sense of our experiences. Although originally oriented towards oral interaction, research on small stories has also been extended to cover narratives in online settings, such as Facebook posts (West 2013), and selfies (Georgakopoulou 2016).

The small stories approach is also suitable for the data analyzed in the present article. As illustrated by the opening quote, the stories told are everyday-like, but permeated by the life-altering issue of chronic illness. That is, they might contain dramatic complications, but they are nevertheless placed in an everyday setting, especially in relation to the photos. Stage's (2017, 17) classification of online cancer narratives as "hybrid" or "big-small" is, in this sense, adequate. With regard to structure, tellership, and temporality, the illness narratives analyzed fall somewhere in-between prototypical narratives and smaller, more fluid, narratives.¹ The posts narrate personal experiences, yet relate to subject matters where tellers, as Page (2018, 10) argues, "engage with large concerns beyond mundane and everyday matters."

3.1 Multimodality and Narrative

Within most narrative research, verbal language has been positioned as the primary narrative medium (cf. Ryan 2004, 11), analytically privileging verbal resources for narrating. Given this position, the issue of visual narratives has been debated; images have been said to 'show' but not 'tell.' Compared to written or spoken narratives, images, for instance, to a large extent lack resources for narrating sequentiality. Whereas some (e.g. Speidel 2013) argue in favor of narrative potential in still images, others, such as Wolf (2003), claim that only a series of still images can tell a story.²

To address the narrative potential and the multimodal character of the data, this article employs a social semiotic perspective (van Leeuwen 2005; Hodge / Kress 1988; Kress 2010). Unlike the referenced debates on single image narration, the article approaches the Instagram posts as multimodal ensembles and narrative wholes, and explores how different semiotic resources are used to narrate about illness. This approach recognizes the interplay between different semiotic resources in inviting narrative interpretations, and how the resources differ in their significance for the story (cf. Page 2010, 8). In the case of Instagram, the visual character of the app requires users to post an image, but this image can vary in how it contributes to the story told.

Semiotic resources also carry different potentials for narrative meaning, i.e. they have different *affordances* (Gibson 1977). A photograph, for instance, orients to a certain way of representing reality, inviting viewers to interpret it *as if* it were a representation of unmediated reality (cf. Kress / Van Leeuwen 2006, 158). Here, the analysis both deals with representational aspects of the images posted, and the social relations that are enacted (cf. Kress / Van Leeuwen 2006; Page 2018, 38). In relation to the latter, Zhao and Zappavigna (2018) demonstrate how different variations of selfies enact intersubjective relations. As an example, inferred or implied selfies, that depict body parts of the photographer, or objects that imply the presence of the photographer, allow viewers to see the represented objects 'as the photographer,' and invite them to share the photographed

experience. Perspective, in this way, invites to social relations between the viewer and the creator of the image.

3.2 Narrative and Identity

Besides the local context on the social media platform, this article also takes an interest in how the illness narratives draw on shared beliefs regarding endometriosis. These beliefs, or ‘cultural storylines,’ can act as a resource for tellers to place their own experience within a larger framework of understanding (cf. Benwell / Stokoe 2006, 43). The reworking of cultural storylines in local storytelling is also connected to identity-work. As De Fina et al. (2006, 7) put forward, tellers construct their identities and position themselves “vis-à-vis others as well as vis-à-vis dominant discourses and master narratives.” Such wider storylines are in the telling given a unique voice, and become anchored in a specific narrative situation.

Narratives, in this sense, have indexical qualities, “invoking and reworking histories of associative meaning, previous interactional contexts and shared resources, including previously told stories, in the course of narrative tellings” (Georgakopoulou 2007, 9). Both linguistic features of stories, and stories as a whole, can index group membership, identity, and social roles (De Fina / Georgakopoulou 2012, 176). As Phillips (2016, 31) notes, even single words and short phrases can function as *narrative icons*, and index broader storylines and shared values. An example of indexical functions specifically relating to the social media format are hashtags, which can invoke group memberships and frame individual experiences within a particular narrative (cf. Zappavigna 2015; Clark 2016).

4. Methodology: The Multimodal Analysis of Narrative Dimensions

Adopting a discourse-analytic perspective, the illness narratives are approached through Ochs and Capps’s (2001) narrative dimensions (Chart 1). This dimensional approach, firstly, recognizes the similarity of narratives to other forms of discourse (Ochs / Capps 2001, 18). Secondly, rather than formal criteria suitable for only a small portion of the narratives we use to make sense of our experiences, the narrative dimensions listed represent possible realizations. Although not always manifest, these dimensions are stipulated to “be always *relevant* to a narrative” (Ochs / Capps 2001, 19) – and to narratives of personal experience, particularly. In this way, the dimensions can be used to analyze a range of narrative practices, and, as Page (2018, 9) notes, explore different narrative examples and their qualities.

<i>Dimension</i>	<i>Possibilities</i>		
Tellership	One active teller	←→	Multiple active co-tellers
Tellability	High	←→	Low
Embeddedness	Detached	←→	Embedded
Linearity	Closed temporal and causal order	←→	Open temporal and causal order
Moral stance	Certain, constant	←→	Uncertain, fluid

Chart 1: Narrative dimensions and possibilities (adapted from Ochs / Capps 2001, 20).

The narrative dimension of 1) *tellership* refers to whether the story is told by one or multiple tellers; 2) *tellability* refers to the value or significance of the story as being worthy of telling, and how tellers, for instance, orient to the story as being relevant, important or unique; 3) *embeddedness* encompasses the relationship between the narrative told and the surrounding context, in this article approached as both the local context on the account (e.g. other posts and posters), and the global context of recurring storylines about endometriosis; 4) *linearity* refers to the organization and structure of events in terms of chronology or sequence of events; 5) *moral stance* refers to the attitude or moral perspective towards the reported events. These dimensions represent a continuum, and can be realized in different ways (cf. Ochs 2004, 281). This study emphasizes the contextual nature of storytelling, considering how these dimensions are re-worked in online contexts, in images and writing. For instance, tellability, as Page (2012, 200) argues, is context-sensitive, and not a static criterion.

In analyzing the realizations of the different narrative dimensions in Instagram posts, this article examines both the discourse features and the visual features of the posted narratives: linguistic choices, address, indexicality, and recontextualizations of previous discourse on the one hand, and visual composition, point of view, and editing on the other hand. As multimodal ensembles, the combination of images and of images and writing, i.e. the image-image and image-text relations, are also analyzed. Here, the analysis deals with what the combination of images affords in narrative meaning, and with the semantic alignment of the propositions represented in the images and texts. In regard to the *ways of telling-sites-tellers* (Georgakopoulou 2007), the analysis cuts across the three interrelated levels, exploring the semiotic resources used to narrate, and how smaller, personal experiences relate to other stories told on the account, and to recurring storylines about endometriosis in society.

5. Data: Instagram as a Locus and Narrative Setting

The analyzed Instagram account is shared by five women, who each post once a week. Since its start in 2016, the account has posted just over 670 posts.³ The general aim of the account, as described in the Instagram *bio*, is to spread knowledge about endometriosis. This aim serves as a frame for all stories told

on the account. All posts also follow a similar structure. They are usually initiated by ‘tagging’ the poster who is writing and end with a visual description that summarizes the visual imagery. Hashtags are also frequently used at the end of the posts.

The data was collected over two months, February and March of 2019, but includes posts from September 2018 to March 2019. Data selection opted to include posts from each of the five posters, although not explicitly aiming at dividing the dataset equally between them. Instead, the data was selected thematically based on the different topics which the narratives focus on (see Chart 2). Two of the topics (Presentations and Diagnosis) are framed as set themes that the posters have agreed to write about. In the case of the ‘My stomach’ topic, the thematic categorization of the posts in this theme was suggested by the close sequential ordering of four of the posts, directly following each other, and the similarities of the posts in terms of images and captions⁴. Eight posts on the topic of pain are also included as pain experiences are both frequently narrated on the account and characteristic of the disease. The thematic data selection thus aspires to reflect some of the more frequently narrated experiences, and the account’s construction as a shared story. The themes, number of posts, and dates of the postings are displayed in Chart 2.

Theme	No. of posts	Dates
Presentations	5	September 2018
Diagnosis	5	February 2019
‘My stomach’	5	December 2018 – March 2019
Pain	8	September 2018 – February 2019

Chart 2: Dataset

Five of the 23 posts contain more than one photo, which is possible via the ‘carousel’ feature on Instagram that allows for up to ten photos per post. In images and written text, the data amounts to 33 images and 5,721 words. The data was collected manually; images were captured through screenshots, and written captions were excerpted into a text file.

The topic of illness also warrants a short ethical discussion on the use and presentation of the data.⁵ Prior to collecting the data, written consent was obtained from all five posters on the account, informing them about participation in the study. The decision to ask for consent thus excluded posts made by guest posters, anonymous posts, as well as any comments responding to the posts. Although the analyzed account is public and openly accessible to everyone, all names, including those of places and hospitals, are excluded from the data presentation. Images that display faces are manipulated to make them less identifiable.

Accordingly, as a consequence of these ethical considerations, the dataset does not include any engagement from the people following the account. However, the dialogical nature of Instagram is still addressed in the analysis through its focus on the ways in which the posters orient to the audience visually and

through writing, as well as on how they relate their stories to the shared space of the account (cf. Methodology above).

6. Analysis

As described in the methodology section, the narrative dimensions of Ochs and Capps (Chart 1) are used as a starting point for exploring the verbal and visual realizations of the illness narratives and for commenting on how the separate stories told relate to other stories told on the account and to recurring narratives about endometriosis in society. The analysis is divided thematically into four sections, each section focusing on the narrative dimensions most significant for the narrative presentation of the theme.

6.1 Introducing Yourself as a Poster

The presentation theme consists of five posts, in which the women introduce themselves as posters. This round of introductions can be seen as a resource for framing the stories told on the account. The tellability (cf. Chart 1) of and the reason for such self-presentations are also explicitly expressed in the first post of the week: “since you are so many new that have stumbled in here recently (so fun!) we thought we would introduce ourselves today.” The reason for telling is thus oriented towards the people following the account. At the same time, these presentations also function to establish a ‘right-to-tell’ on the account, since they allow the posters to present their particular experiences as authentic endometriosis experiences. The images posted all present the tellers visually to the audience, in most cases through selfies (see Figure 1) of them looking directly into the camera. In this way, a relationship between the audience and the poster is enacted (cf. Zhao / Zappavigna 2018). In the case of the image to the right, the raised hand is also hinting at a wave.



Figure 1: Two selfies introducing the posters

In terms of structure, all presentations follow the same pattern. First, the tellers present their age, occupation, and hobbies in one paragraph. Next, they narrate how they received their diagnosis (1), followed by an account of how they are doing today (2).

Jag fick mina första ordentliga symptom på endo i gymnasiet. [...] Det dröjde många, många år och undersökningar, en operation och 40 minuters magnetkameraundersökning (MR) innan min endo upptäcktes.⁶ (1)

I got my first real symptoms of endo in high school. [...] It took many, many years and examinations, a surgery and a 40 min magnetic camera scan (MR) before my endo was discovered.

Idag är jag ännu inte smärtfri, går dagligen med lätt/medel molande smärta i mage, ryggslut och ner i benen. Plus tröttheten på det. Sen kommer dagarna där man har fruktansvärt ont. Har nyligen börjat med amitriptylin som jag hoppas ska hjälpa och har även hormonspiral sen ett år tillbaka. (2)

Today I am not yet pain free, have daily light/dull pain in stomach, lower back and down in the legs. Plus the fatigue. Then come the days when you are in terrible pain. Have recently started with amitriptyline that I hope will help and since a year back I also have a hormonal IUD.

These presentations, effectively, form an overarching frame for the personal stories told on the account. The narrative dimension of embeddedness (cf. Chart 1) is, in this respect, salient in the presentations; the basic information of who the posters are, what they have been through, and how they are feeling today works to establish a context in the shared space of the account. Indirectly, the presentations of the posters also introduce the particular topics that they will narrate, or topics that their narrations have dealt with previously. See (3) and (4):

Ni har kunnat följa mig på instastory i veckan då jag genomgått en radikal hysterektomi. [...] Det finns under höjdpunkter en som heter hysterektomi. Där finns alla jag lagt upp som handlat om min hysterektomi. Jag kommer även fortsätta lägga upp uppdateringar om mitt läge efter denna operation. (3)

You have been able to follow me on instastory this week when I've gone through a radical hysterectomy. [...] Under highlights⁷ there is one that is called hysterectomy. There you have all that I've posted that has been about my hysterectomy. I will continue to post updates about my state after this surgery.

Barnlösheten är bland det värsta för mig, det som påverkar mig mest och som bryter ner mig. Det är barnlösheten jag oftast skriver om, här får jag vara ledsen och svag, här får jag sätta ord på mina känslor, här får jag vara rädd. (4)

The childlessness is among the worst things for me, the thing that affects me the most and breaks me down. It's the childlessness that I most often write about, here I get to be sad and weak, here I can put my feelings into words, here I get to be scared.

As seen in (3), where the poster relates to stories told or yet to be told about her hysterectomy, the presentations embed previous and future narratives within a specific poster's ongoing experience. In the case of (4), the presentation is embedded in the habitual topic of childlessness, where the account is positioned as a safe place for sharing: "here I get to be sad and weak." By referencing previous and future stories, this embeddedness is also an orientation towards the structure of the shared account, which prompts both unity in the stories, and recognizable posters. In a similar manner as with the images posted, the captions thus make the tellers and their ongoing stories visible and recognizable on the account.

6.2 Working Hard to Get a Diagnosis

Although many of the mundane storytelling practices on social media tend to fall outside those of canonical narratives, there are examples of stories told retrospectively and with a clear resolution. This is the case of the diagnosis stories, where the posters share how they received their diagnosis. This sharing is based on a need to motivate the audience, as described in the first post in the theme:

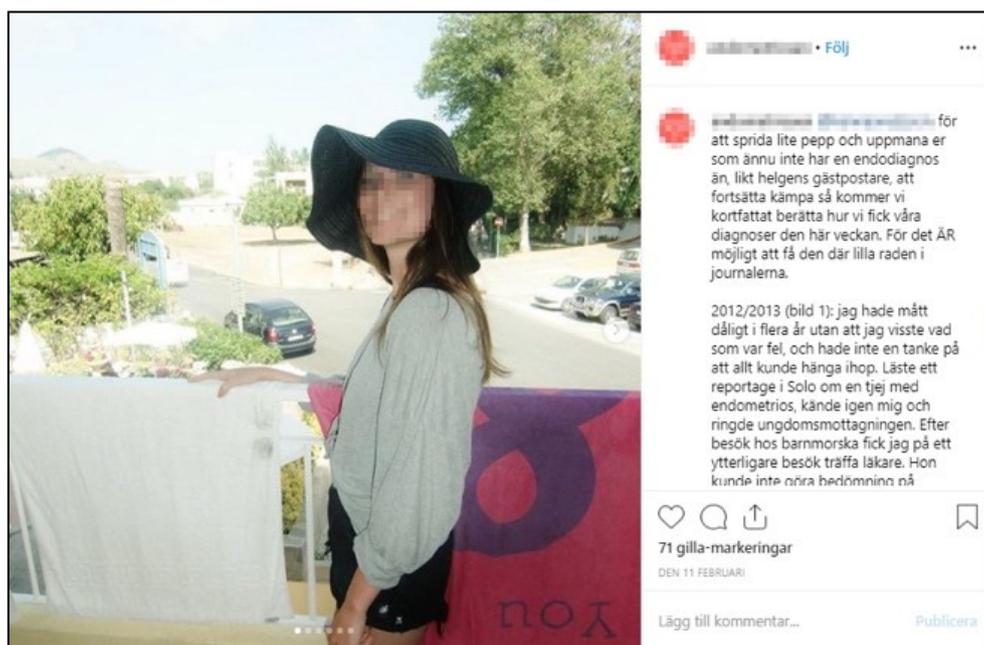
För att sprida lite pepp och uppmana er som ännu inte har en endodiagnos än, likt helgens gästpostare, att fortsätta kämpa så kommer vi kortfattat berätta hur vi fick våra diagnoser den här veckan. För det ÄR möjligt att få den där lilla raden i journalerna. (5)

In order to encourage you and urge those of you, like this weekend's guest poster, who don't yet have an endo diagnosis to keep fighting, we will briefly tell you about how we got our diagnoses this week. Because it IS possible to get that small line of writing in the medical records.

Framed as something hard to get and the result of a fight, for instance, signaled through the capital letters in "IS," the diagnosis stories become highly tellable. As opposed to personal reasons for sharing, the motive for telling is based on the audience's need for motivation and encouragement. In this way, the audience, and more specifically those "who don't yet have an endo diagnosis," are directly addressed. It is worth noting that the orientation to tellability here presupposes that the audience has endometriosis, and it appears to be unthinkable that one can be wrong in suspecting it; rather, if the audience is without a diagnosis, they should just keep fighting until they get one.

Since the first post of the theme framed a particular diagnosis story, one of having to fight hard to get a diagnosis, other posters subsequently attend to the expectations of the audience, and the tellability of the story. One poster, for instance, initially hedges her story about getting a diagnosis quickly with the phrasing "I should consider myself lucky." This hedging demonstrates awareness of the atypical nature of her experience, since the typical endometriosis experience, and the diagnosis stories told on the account, normally involve the opposite. In this sense, the poster embeds her story in the theme and the shared space of the account, thus also connecting herself experientially to the activism on the account.

Further, the narrative dimension of linearity (cf. Chart 1) is salient in the diagnosis stories; both visually and verbally, the stories have a clear temporal and sequential progression, where separate events leading up to the diagnosis are brought together in a single story. In narrating their diagnosis stories, three of the tellers make use of Instagram's carousel feature, creating a timeline with photos depicting a 'before' and 'after' in terms of their diagnosis. One teller posts three photos of herself with different friends, taken before the diagnosis. Another teller posts two photos, one before the surgery that confirmed the diagnosis and one after. The third example of a diagnosis story making use of a series of images is displayed in Figure 2.



2012/2013 (photo 1): I had been feeling bad for years without knowing what was wrong, and I didn't have a clue about that it all could be connected. Read a story in Solo about a girl with endometriosis, and recognized myself in it and called the youth clinic. After a visit with a midwife I got to see a doctor at an additional visit. She could not make an assessment at the youth clinic, and sent a referral to the hospital. TVUS [Transvaginal Ultrasound] was done but found nothing wrong. Got mini pills as treatment that hardly helped.



Figure 2: A diagnosis story using a series of images

Figure 2 displays the first post of the week that starts off the theme, with the accompanying caption of the first photo.⁸ In terms of structural features and linearity, the post has a closed temporal sequence that is achieved via the interplay between images and captions. By means of the carousel feature, a sequential timeline with life events and photos is created. These events are located in the past through past tense expressions, such as “read a story” and “recognized myself in it.” Similarly, the use of headings, such as “2012/2013” (photo 1), and a colon divides the written content into temporally delimited chunks.

Visually, the series of photos also tells a story in past tense. The caption in Figure 2 describes how the teller was suspecting a diagnosis, but it was not yet confirmed by doctors. This written account is linked to the first photo, which appears to be a vacation snapshot of the poster smiling. In the two subsequent photos, the poster is seen in a group photo, and photographed sitting on a car. The uniform clothing in the second photo suggests that the four women are work colleagues, and the Norwegian flag seen in the back of the photo situates

the scene in Norway. The faces of these work colleagues are also replaced by smileys, probably due to the public character of the Instagram account. In this way, old photos are recontextualized and repurposed as part of a more widely shared diagnosis story.

By means of the fourth and fifth image, the teller also effectively moves herself into a medical context. The inferred selfie in the fourth photo, depicting the lower body of the teller in hospital clothes, and the following mirrored selfie in a hospital gown, place her in a hospital setting and subsequently turn her into a patient. The composition of the selfies invites the audience to share this hospital experience with her (cf. Zhao / Zappavigna 2018). The series of photos thus affords a progression in time that also relates to space and place; the teller is moved from a seemingly undiagnosed state to being anchored in a medical context. Similar to the sequential affordance of writing, this combination of images creates narrative sequentiality.

While the use of images constructs time and place, and tells the story in broad brushstrokes, the struggles and twists and turns of the story seem more easily conveyed in writing. In the caption for 2014/2015, for instance, the poster describes how she “nagged to get a surgery.” Similarly, the failures and lack of a diagnosis that are conveyed in the writing are less apparent in the image, which only shows the last scan that led to a diagnosis. The resolutions of the stories are also more prominent in written form than in the visual features, most stories in the theme ending precisely with the information that the poster was finally diagnosed: “4 weeks later I had the surgery and the diagnosis was established.”

In Figure 2, however, the last photo is in itself an evolution of the story told. In the caption, the photo is described as a “bonus,” without any of the year-based headings or past tense expressions that appear in the rest of the post. In this way, the actual proposition is represented in the image. The photo depicts a road sign, with the text “Allt kommer att bli bra” (“Everything is going to be all right”). Similarly to the anticipatory ‘projections’ studied by Georgakopoulou (2007, 47), this road sign indexes direction and a move forward, which can be interpreted as ‘this is where we are going.’ This positive imagery also connects back to the tellability of the story, namely to encourage the audience to keep fighting.

Another salient feature of the diagnosis stories is how the stories are embedded in recurring storylines and experiences among endometriosis patients. This invoking and indexing of previously told stories can be seen as a type of thematic embeddedness (Ochs / Capps 2001, 37), see (6) and (7):

När jag var 15 sökte jag hjälp första gången. ‘Det ska göra ont att ha mens’ och ‘det gör ont att vara kvinna.’ (6)

When I was 15 I sought help for the first time. ‘It’s supposed to hurt having your period’ and ‘it hurts being a woman.’

De sa att tyvärr så hjälper inte p-piller alla kvinnor utan det är bara att gilla läget. Ta I-pren när det är som värst. Det gör ont att ha mens och funkar inte p-piller så finns det ingen annan hjälp att få. Genom alla år har jag alltså köpt detta. (7)

They said that unfortunately birth control won’t help all women but you just have to accept it. Take an advil when it’s the worst. It hurts having your period and if

the birth control doesn't work then there is no other help to get. Throughout all the years, then, I've bought this.

In (6) and (7), the tellers align their stories to a larger narrative regarding the difficulties endometriosis patients encounter in receiving care. The quotation marks and indirect speech that recontextualize previous healthcare encounters can be seen as a way of voicing common understandings of the disease, and the female body. By means of these retellings, such as “it hurts being a woman” in (6), the personal experiences are anchored in a wider narrative. Similar to narrative icons, such short phrases can index other stories circulating about the disease, ultimately also legitimizing and lending weight to the specific poster's story.

6.3 'My Stomach'

With regard to the narrative dimension of tellership, the 'My stomach' theme is an example of how individual stories can contribute to a *co-tellership* and a jointly produced storyline. Although the tellership is structurally divided in separate textual units, the posters draw on the same visual and verbal resources for making sense of the chronic disease. The five posts of the theme consists of seven photos of stomachs (see Figure 3), as two of the posts make use of the carousel feature (the last two in the first row and the first two in the second).



Figure 3: Stomach representations

Visually, the posts make use of the same strategies for depicting the stomach. The images are naturalistic (Kress / Van Leeuwen 2006, 158) and depict stomachs with scars, stretchmarks, and bruises. As photographs, they invite to an understanding of the images as the reality behind the disease. Further, all images place the stomach in the center as the focal point for the viewer, showing only part of the interior, the rest of the body, and clothing. The audience is thus invited to see all of the stomach, but very little besides the stomach. In relation to the use of multiple photos, the carousel feature is utilized to show even more

of the poster's own stomach, either from a different angle, or a different part of the stomach.

All images are also concrete and specific; they depict the specific posters' stomachs, and not a stomach in general terms. Unlike stock photos, which tend to afford genericity, and where depicted persons are not of relevance as individuals (cf. Thompson 2012a), the tellers and their stomachs are central to the narratives. Likewise, the photos appear to be taken specifically for the 'My stomach' stories, as opposed to repurposed old photos (cf. Figure 2). The images posted are also positioned as the key aspect in terms of tellability (cf. Chart 1), as several captions start off by pointing to the photo: "This is what my stomach looks like today." This focus places the reason for telling on the lack of representation of these stomachs and endometriosis, as something yet to be visualized and narrated. All the visual descriptions of the posts also stress the visible effects of the disease; the presence of scars, bandaids, and stretchmarks, some also commenting on how the photos show the size of the stomach. Similar to previous themes, tellability thus appears to be directed towards the audience.

In terms of linearity (cf. Chart 1), the stories told are, to a large extent, open-ended, with few markers of temporal or causal progression. Instead, the photos posted provide a snapshot of the present appearance of the tellers' stomachs. In the written captions, however, there are expressions of shifts of viewpoint and opinions over time, as in (8):

Min mage. Som jag har batat den. Jag har batat den för att den gör ont. För att den inte tål att äta allt. För att den var tjock. För att den inte har gett mig det jag önskat mest av allt, barn. Den är ärrig, full med bristningar jag fick redan som tonåring, som sedan växte när mitt barn växte. Den är mjuk och fluffig. Den gör fortfarande ont, men jag har lärt mig tricks som (ibland) lindrar. Den är fortfarande tjock, men det är okej. Bristningarna kommer inte försvinna, de kommer troligen växa. Ärren kommer finnas kvar, möjligen blekna. Den kommer troligen alltid vara mjuk och fluffig och den kommer aldrig tåla det den inte tål. Jag ser inte längre någon anledning att bata min mage. (8)

My stomach. How I've hated it. I've hated it because it hurts. Because it can't eat everything. Because it was fat. Because it hasn't given me what I wanted the most, kids. It's scary, full of stretchmarks I got already as a teenager, that later grew when my baby grew. It's soft and fluffy. It still hurts, but I have learnt tricks that (sometimes) eases the pain. It's still fat, but that's okay. The stretchmarks won't disappear, they will probably grow. The scars will remain, possibly fade. It will probably always be soft and fluffy and it will never be able to eat what it can't eat. I no longer see any point in hating my stomach.

In (8), the temporal progression is achieved with a shift between a then and a now, as the teller uses past and present tense to describe an understanding of her own stomach that has developed over time: "Because it was fat [...] It's still fat, but that's okay." The temporal adverbs "still" and "no longer" similarly contribute to the temporal shift in the narrative, from a previous bad state, to a point of acceptance of what is displayed in the photo. This reflective character, and explicit sense-making of the experiences, is also present in several posts, aligning the written text with the naturalistic, 'real' stomachs depicted in the images. In Figure 4, the poster explicitly orients to the difficulty of making sense of her stomach and the disease. As a means of sorting out this difficulty, she draws on a larger narrative of 'fighting' one's illness:



Figure 4: The fighting stomach

As seen in Figure 4, the teller draws on a warrior narrative, describing herself as an “endo-warrior.” The stomach is then understood in relation to this narrative; like other warriors, she has received and will continue to receive scars from the fights. Similar warrior expressions are found in several other ‘My stomach’ stories, many using the verb “kämpa” (“fight”) to describe what their stomachs are doing. In the second photo of Figure 3, this fight is referenced both verbally and visually, as the photo depicts the poster’s stomach with the words “Endofighter” written with a felt pen, followed by a ribbon that indexes the endometriosis awareness movement. By using such war metaphors, the tellers position themselves as active, determined, and not giving up (cf. Semino et al. 2016, 639).

The narrated fight is also indexed through hashtags. Besides common hashtags used in most posts in the data, affiliating with the endometriosis awareness movement, several posters make use of hashtags containing the word “fight,” such as “#fight” and “#fightendo.” Alongside these hashtags, there are also hashtags pertaining to the individual poster, and the personal story told. In Figure 4, the hashtag “#hysterektomi” (“hysterectomy”) is used, whereas the post in (8) indexes stories relating to the difficulties of having children, and body positivity; “#infertilitysucks” and “#allastorlekarärvackra” (“all sizes are

beautiful”). These hashtags link to both previous and ongoing topics of the posts, embedding the ‘My stomach’ fight narratives within the stories told throughout the account. As several of the hashtags are in English, the personal experiences are also connected to stories that reach beyond the Swedish speaking community.

Another notable feature of the theme is how the posters relate to their stomachs, which corresponds to the narrative dimension of moral stance. In Figure 4, appreciation towards the stomach is formulated by direct address, using the second person pronoun “you:” “So thank you lovely stomach for reminding me of that.” In (9), the style of address shifts mid-post:

Så här ser min mage ut idag. Endometriosen syns på utsidan. Jag slängs mellan att hata och älska min mage. Tänk vad mycket ont den förorsakat i så många år, och tänk allt som komma skall. Men älskade mage, det är ju inte ditt fel. Det är ju något främmande i dig som du drabbats av. Vad stark du är som kämpar på. (9)

This is what my stomach looks like today. The endometriosis is visible on the outside. I'm torn between hating and loving my stomach. Think about all the pain it has caused during so many years, and think about all that is yet to come. But beloved stomach, it's not your fault. You know, there is something foreign in you that has affected you. How strong you are that keep on fighting.

In (9), the teller starts off by using third person “it” and referring to the stomach from a first-person perspective. Later on in the post, she shifts to direct address: “it's not your fault [...] how strong you are.” In other posts, although using third person address, the stomach is similarly personified and assigned actor-like qualities: “My stomach, on the other hand, the one who loves summer, sun and swims [...]” The stomachs are in this way separated from the disease that resides in it – described as a “foreign” or “uninvited guest” – thus possibly making it easier for the tellers to love their stomachs. The familiar address and the expressions of gratitude can here be seen as indications of moral stance; the tellers position themselves as being aware of the problems with hating one's body. By means of the reflective character of the narratives, and the temporal shifts, the tellers go from ‘not knowing’ to ‘knowing’ about their experience in a good way. In (8) this knowledgeability is seen in how the teller reports how her body has stayed the same but her attitude towards it has changed: “I no longer see any point in hating my stomach.” Morally, then, the tellers come across as fighting the disease as well as the negative emotions that it creates.

6.4 Narrating Invisible Pain

Since the most characteristic symptom of endometriosis is pelvic pain, or period pain, posts narrating about pain are frequent on the account. In contrast to the thematic orientation of the other themes, the pain narratives are collected over a longer time span, affecting both the narratives' tellability and their temporal progression. See (10) and (11):

Hoppas, här flyger dagarna bara fram. Det är torsdag och min dag igen. Jag har varit i ett skov med mycket värk i lederna och mina tarmar bråkar. (10)

Oh god, the days just fly by here. It's Thursday and my day again. I've been in a relapse with a lot of pain in the joints and my bowels are messing with me.

På torsdag är det 21 dagar sedan jag tog min sista enanton-spruta vilket innebär att det är fritt fram att ta nästa. Jag längtar! (11)

On Thursday it's 21 days since I took my last enantone injection which means that it's go ahead for the next. I can't wait!

Compared to the tellability of previous themes, the pain narratives are more oriented to recency as a reason for telling. The tellers frequently make reference to a “now,” “right now,” or “tomorrow,” both connecting back to previous experiences, and describing their present status. The reported events can in this sense be classified as ‘this has happened since I last posted,’ embedding them in the unfolding personal narrative. In (10), for instance, the teller addresses the time that has passed since the last update: “It's Thursday and my day again,” followed by an account of how she is feeling. This embeddedness also functions as an orientation towards the structure of the account, and the audience, who expect weekly updates from each of the five individuals.

At the same time as the stories appear to privilege recency, there are also examples of pain narratives orienting to the informative stance on the account. Rather than strictly updating, these posts also inform the audience about the invisible and unknown nature of the disease. See (12) and (13) that are the continuations of (10) and (11):

Att ha problem med tarmarna är inte ovanligt när man har endometrios. Den kan orsaka att tarmen blir inflammerad och därav orsaka mycket smärta och även blödningar. [...] (12)

Having problems with your bowels is not unusual when you have endometriosis. It can cause the bowels to become inflamed and therefore cause a lot of pain and also bleedings. [...]

Dagarna innan är värken och symptomen mer påfrestande än annars. Vad nu “än annars” betyder? Visst har jag inte så ont som jag vet att jag KAN ha, är inte ens i närheten, men jag har det fortfarande besvärligt. Ihållande smärta i lumske som strålar ner i benet, huggande smärta i magen som överraskar mig, ont och stel i muskler och leder generellt, trötthet och huvudvärk utgör min lista just nu. Ändå skulle nog ingen vilja satsa pengar på att jag har ont. Det syns ju liksom inte. [...] (13)

The pain and symptoms are more trying the days before than otherwise. Whatever “otherwise” means? Sure, I'm not in as much pain as I know I CAN be in, not even close, but I'm still struggling. Persisting pain that radiates down to the leg, stabbing pain in the stomach that surprises me, pain and stiffness in muscles and joints in general, tiredness and headache is on my list at the moment. Still, no one would bet money on the fact that I am in pain. You can't really tell, you know. [...]

In the examples, both tellers situate their personal, in-the-moment experience in relation to broader issues associated with endometriosis. In (12), the poster uses the generic “man” (“you”) and refers to the symptoms described as “not unusual.” This shift between describing causes in a more formal manner and the personal story is less apparent in (13). Instead, the personal experience acts as an example that others can identify with. In both cases, the stories of subjective and invisible pain are accompanied by ‘image macros’ that combine image and text to convey their message (Figure 5).



Figure 5: Pain memes

As memes, the images are culturally recognizable and promote affiliation. Similar to the informative written accounts, they invite a shared sense of the pain that is described, for instance, as in the second meme, where a person sits on fire. Both images are also semantically aligned with the written captions of the posts, addressing the difficulty of conveying the invisible endometriosis pain. In other pain narratives, the images posted vary in how they relate to the written captions (Figure 6).



Figure 6: Three pain images

In the first image, the photo works to enhance the propositions of pain during egg retrieval told in the written text. The photo is taken in the moment after the reported events, visible in the hospital clothes the teller is wearing. Whereas this post uses a more documentary photography that works to enhance the written narrative, the two others demonstrate a dynamic interplay between images and text. In these posts, images and texts are semantically misaligned, as the teller describes the false appearance of the photos. The middle photo, a mirrored selfie of the poster smiling, is described as untrue: “the outside says something, the inside something completely different.” The teller then describes the invisible pain that she is dealing with at the moment of posting. In the third photo, by the same poster, a photographed note with the text “Stark” (“Strong”) is refuted in the last sentence of the caption: “Strong? Not right now.” In terms of narrative potentials, the images in Figure 6 have the potential to both strengthen and contradict the written stories.

The orientation to moral stance (cf. Chart 1) is also salient in the pain narratives, as tellers convey disbelief and doubts regarding the healthcare system's competence. This is primarily achieved by recontextualizing previous healthcare encounters, serving as illustrative examples and resources for storying pain-related experiences. As such, the narratives serve to affirm a specific moral perspective (cf. Ochs 2004, 284), one of the teller as knowledgeable, and the healthcare system as ignorant:

Häromdagen ringde jag kvinnokliniken för att få smärtstillande utskrivet, förklarade att dom jag provat inte hjälpt, vilket är [räknar upp smärtstillande]. Fick till svar att jag kunde ju prova köpa vanliga alvedon 😏 Ja för dom lär ju hjälpa då, eller inte.. (14)

The other day I called the women's clinic to get some painkillers prescribed, explained that the ones I've tried haven't helped, which is [lists painkillers]. The answer I got was that I could try buying regular advil 😏 Yeah because they will help, or not..

[...] får jag bemöta "om du äter antiinflammatorisk mat?" och "om inte en till citodon hjälper så testa alvedon 500mg och värme", som sköterskan på gynakuten sa på telefon i lördags när jag hade så ont att jag stammade. Jag vill tro att det är av välvilja men det upplevs som att den här sjukdomen inte är på allvar. Och som om alla andra vet mer än jag om den kropp jag handskas med 24 timmar om dygnet, och ständigt reflekterar kring. (15)

[...] I have to face "do you eat anti-inflammatory food?" and "if citodon doesn't help then try Advil 500mg and heat", like the nurse at the gynecological ER said on the phone Saturday when I was in so much pain I stuttered. I want to believe that it's of benevolence but it's perceived as if this disease isn't real. And like everyone else knows more about the body I deal with 24 hours a day, and constantly reflect over.

In narrating their experiences, and recontextualizing the voices of nurses and doctors, the tellers work to portray the comportment of the healthcare providers "in relation to standards of right and wrong" (Ochs / Capps 2001, 225). In (14), for instance, the recontextualization of the nurse's advice is coupled with irony, ridiculing the suggestion to take normal painkillers by means of the emoji with rolling eyes, and the "or not" followed by two dots. In this way, the personal pain experiences are anchored in a wider critique, as expressed in (15), "it's perceived as if this disease isn't real." In both examples, the recontextualizations can also be seen as a resource for creating an image of oneself as competent. By voicing 'unreasonable' advice, the tellers position themselves as knowledgeable, and as experts.

7. Concluding Discussion

Recent developments in the way we communicate about health and illness, and new spaces for sharing online, have led to the storying of previously unknown illness experiences. The analysis of the shared Instagram account for narrating about endometriosis in this article sheds light on these contemporary illness narratives, and the ways in which personal stories are tied to larger, recurring stories about being ill.

With regard to the ways of telling, the analysis of the different semiotic resources used to narrate about health and illness and, more specifically,

endometriosis, demonstrates a dynamic interplay of images and texts. In the multimodal ensembles of the posts, visual and verbal resources work together to convey narrative meaning, although taking on different forms. As shown in the analysis, the carousel feature of Instagram affords a temporal and sequential progression that narrates a ‘before’ and ‘after’; through the series of repurposed images, the teller is effectively moved from a place before diagnosis to a medical context. The documentary photography of the tellers in hospital clothes also works to enhance the story told in writing, showing the ‘reality’ and everyday experience of being ill. The perspective in these images – selfies or inferred selfies – invites the audience to share these authentic illness experiences. In other cases, illness is narrated by posting an image that contradicts the caption. A happy mirrored selfie, in this manner, has the twofold function of showing how the teller is doing, and commenting on the invisible nature of endometriosis pain. As the future-pointing road sign demonstrates, images can also have additive functions, conveying propositions not available in the captions.

The social space of the account as shared and activist also shapes the narratives. As shown in the analysis, separate posts relate to the story on the account as a whole in terms of both structure and content. The ongoing nature and turn-taking format results in orientations towards previous stories and present ones; the presentation theme connects past, present, and future stories to a specific poster, and in the pain narratives, the specific pain story is situated in relation to the last post (cf. Stage 2017; Page 2012). Further, the endometriosis stories told are primarily outward-pointing, and tellable in relation to the audience, who are assumed to be fellow ‘endo-fighters.’ Here, the activist framing and awareness-raising aim of the account leads to certain reasons for sharing – in the case of the diagnosis stories, to motivate and inspire. This tellability also aligns with the larger co-told story in the theme – one of having to fight hard to get a diagnosis.

With reference to the tellers, and the particular discourses and identities that the illness narratives index, the stories appear to center around different aspects of knowledgeability. By giving voice to previous healthcare experiences, and indexing recurring storylines about ‘fighting’ the invisible endometriosis, the tellers position themselves as competent, active, and moral persons who understand the disease. In the case of the ‘My stomach’ theme, the morally important self-acceptance is also expressed through the reflective character and the personification of the stomachs. Similarly, the invoking of recurring storylines in the posts ties this knowledgeability to awareness regarding the larger story of endometriosis.

In this way, the account is not just a setting for narrating personal experiences of endometriosis, but also a space in which particular personal experiences are relevant and tellable, as one teller’s disclaimer about the atypical nature of her diagnosis story demonstrates. By means of visual and verbal resources, separate posts thus appear to be embedded in three ways; in relation to the ongoing personal story, in relation to the account, and in relation to the typical or larger narrative about endometriosis. This points to the complex interdependencies of

illness experiences and spaces for narrating, especially intricate in the context-rich settings of social media.

Methodologically, the narrative dimensions prove to be a valuable tool for the analysis of these illness narratives. The collaborative and episodically told stories rework ideas of tellership, tellability, and embeddedness, and the relationships between them. In this way, the orientation to the co-told and shared story on the account points to how these narrative dimensions are co-constructive and interwoven. Future work on online storytelling can benefit from recognizing the emergent and dynamic relationships between different narrative dimensions, as this allows the analysis to attend to media-specific features.

This article also points to the workings of health discourse, more generally. Narrativizing illness in this format appears to function as a resource for identity construction, where patients can narrate their way into a community of fellow sufferers. Although online storytelling has led to an increase in visibility of experiences of being unwell, the illness narratives of this article also give rise to questions regarding master narratives and alternative ones, and the boundaries between them. As discussed, the analysis shows how a certain type of story, and a certain type of knowledgeable patient, are brought forward. In contributing to a counter-narrative about health and how the female body is supposed to function, the tellers might also possibly be approaching another, dominant, story – one where only specific endometriosis experiences fit in.

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¹ Several scholars have also questioned the big / small divide, claiming that such a division is an oversimplification (cf. Wilson / Stapleton 2010).

² The issue of how to address the visual contra the verbal is also prevalent in other research fields. As an example, scholars of multimodality have questioned the applicability of models intended for verbal language to the analysis of images (cf. Ledin / Machin 2018).

³ Accessed July 2, 2019.

⁴ In keeping with Instagram vocabulary, I use 'caption' to refer to the written content accompanying the image posted. Although the term might suggest a hierarchical order, where writing is secondary to images, I analyze the captions as part of the multimodal ensembles of Instagram posts.

⁵ The larger project that this study forms a part of has been ethically vetted and approved by the regional ethical review board in Uppsala, Sweden, <https://etikprovning.se/>.

⁶ The English translations of the original posts were made by the author, with the aim of staying as close as possible to the original formulations (e.g. with regard to spelling, punctuation, and word order). Typing errors without analytical importance are not reproduced in the English translations.

⁷ 'Highlights' are archived stories, usually thematically organized, and located in the section below the Instagram bio.

⁸ The first part of the post, describing the reason for telling, is reproduced in (5). The English translation accompanying the original Swedish post therefore only includes the caption intended for the first photo in the series.

⁹ Four of these stomach posts appear only days apart, and form a cluster of images on the Instagram feed of the account, whereas the first photo was posted a few months earlier.