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Blogging and breast cancer: Narrating one's life, body and self on the Internet



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SYNOPSIS

Living with breast cancer requires new ways of relating to one's changed self, life and body. The aim of this study is to understand how women with breast cancer make sense of their altered selves while narrating their story on a personal weblog. The methodology used is a qualitative, narrative approach that focuses on subjective experiences as narrated within five sampled weblogs. Four types of self-narration are identified: The Estranged Cancer Patient, The Transient, The Heroic Survivor and The Disfigured Woman/Girl. The progression of these different self-narrations implies a particular process of sense-making by these women: re-appropriating themselves while senses of estrangement linger. This process is co-determined by the specificity of weblogs as a medium. Ultimately, the findings in this study suggest that this mediation both reinforces greater freedom in self-narration – as feminist theorists in the 1990s claimed – yet at the same time, it offers space to affirm stereotypes and conventions.

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Introduction

Breast cancer changes the lives and bodies of women.¹ These women may be confronted with scarring, the loss of one or both breasts, lymphedema due to surgical treatment and their own mortality. They may also have to contend with persistent pain and fatigue, temporary hair loss and nausea, general joint stiffness, increase in body weight, heart problems and loss of bodily functions due to various adjuvant treatments, such as radiation therapy, chemotherapy, hormone therapy, and immunotherapy. Consequently, the ways these women understand themselves, their lives and their bodies are severely disrupted during and after breast cancer treatment. Living with breast cancer thus requires new ways of relating and giving meaning to a woman's changed self, life and body.

This article describes the ways in which women who have (had) breast cancer endow meaning to themselves, their lives and bodies through the autobiographical stories

they tell and re-tell on their personal weblogs. Linking up with the hermeneutical tradition, we start from the general assumption that people make sense of themselves within and through the telling and re-telling of stories (Ricoeur, 1991; Widdershoven, 1993). People *narrate themselves*; we constantly make sense of what we experience by fitting these experiences into stories that express how we think of ourselves, of our identity, of who we are. Currently, a growing body of literature recognizes the significance of the Internet as a space where people compose and circulate such narratives (Broom, 2001; Orgad, 2005; Paasonen, 2002; Pitts, 2004; Turkle, 1995). More and more people have access to the Internet and a high number of users actively share their stories online. Further, as we will outline below, the Internet is a particular and distinct medium; indeed, online autobiographical storytelling differs from offline storytelling (Keim-Malpass & Steeves, 2012; Orgad, 2005; Pitts, 2004). One of the most explicit and typical manifestations of online autobiographical storytelling can be seen on personal weblogs ('blogs'). It will analyze how women with breast cancer make sense of their altered self, life and body while narrating their story on a blog.

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This article has a two-fold structure: (1) it provides a theoretical outline of the scholarly debates on the sense making potential of offline and particularly online storytelling about illness experiences in general, and breast cancer experiences in specific, and (2) it provides an in-depth analysis of five personal blogs on breast cancer on the basis of a qualitative empirical study. Subsequently, the results of our empirical study are discussed in light of the debates on storytelling.

Offline and online storytelling

The 1970s witnessed an overwhelming emergence of autobiographical accounts of breast cancer (Couser, 1997). Over the past three decades, these kinds of autobiographies developed into a genre of first-person breast cancer stories (Ehrenreich, 2001). The development of this genre coincides with the rise of the post-modern society and its emphasis on individualism and activism. It is therefore claimed that in telling their breast cancer stories, women perform autobiographical writing as an ethical and political act of both reclaiming their own story with a female voice, as well as of empowering other women (Lorde, 1980; Morris, 2000). In addition to being politically charged, narratives like these also include reflections on one's own self, body and identity. In her breast cancer memoir, 'The Cancer Journals', Audre Lorde (1980), for instance, writes "I did not have to look down at the bandages on my chest to know that I did not feel the same as before the surgery. But I still felt like myself, like Audre." (49). This quote is an explicit example of giving words to the issue of identity, which is an issue that is often meditated upon by breast cancer autobiographers: now that I have (had) breast cancer, who am I? (Herndl, 2006).

Breast cancer gives rise to these types of self-reflection since it interrupts the course of one's life and normal experience of one's body. Within the larger context of becoming seriously ill (and subsequently developing a chronic illness), Arthur Frank (1995) calls this jarring experience a temporal and narrative "chaos" (97): the stories once told about people's healthy, unblemished past do not seem to belong to 'them' anymore and the stories about their formerly imagined healthy, even living future lose their meaning. Consequently, their actual presence feels false. The only way out of this chaos is to take stock of what survives the cancerous experience by telling altered or altogether new autobiographical (illness) stories (Frank, 1995).

While autobiographies are obviously very personal, they do not emerge in a vacuum. People make sense of what they experience by adhering to shared symbols, norms and metaphors (Berghmans, 2012). Accordingly, many theorists argue that breast cancer accounts generally reiterate and affirm mainstream conceptions, stereotypes, norms and ideologies of illness, cancer, beauty and gender. Breast cancer experiences, they argue, are often framed in ways that assume heterosexuality (Lorde, 1980), that emphasize women's positive attitude toward life (Herndl, 2006), and that pressure women to look 'normal' (i.e. healthy) and to adopt beautification techniques (Broom, 2001; Wilkonson & Kitlinger, 1993). Erving Goffman calls this the "management of spoiled identity": the effort of the individual that diverts from the expected norm to present herself as an ordinary person while "not necessarily making a secret of [her] failing" (1983, 31). Adhering to such norms and

expectations within their own storytelling can be both helpful and harmful for women who have (had) breast cancer. It may be hopeful to see their return to normality being expected (Frank, 1995). However, these norms may also give rise to a sense of shame by glossing over and thus discrediting the unpleasant, painful aspects of the breast cancer experience (Broom, 2001; Lorde, 1980; Sontag, 1990).

Even before the Internet became a popular option for telling breast cancer stories, Victoria Broom questioned whether the Internet would be a place where these conventional norms and ideologies are repeated, or, instead, offer a space for alternative stories about the breast cancer experience (Broom, 2001). This question was motivated by the rise of theories on the liberating potential of storytelling online for definitions of selves and bodies in the 1990s. A number of scholars assumed and celebrated the reversibility, interactivity and disembodied nature of the Internet, its dynamic use of hypertext and its lack of socio-cultural context cues. These features, they claimed, stimulate a disruption in the 'offline' ways in which we define ourselves through storytelling. Reversibility may stimulate a constant and highly changing performance of the self (Poster, 1995; Waskul, Douglass, & Edgley, 2000). The potential of worldwide networking on the Net may facilitate women's formation of online spaces of dialog and resistance (Plant, 2000; Sundén, 2001). Hypertext may enable stories to be told in a non-linear, a-synchronic way, fostering a fluid, dynamic performance of self (Beetham, 2006; de Mul, 2010; Gergen, 1991). Finally, as physical bodies are absent on the Internet this may leave us with greater freedom to perform our bodies through text (i.e. words and codes) and audio-visual material (i.e. sound, pictures, videos) resulting in multiple online identities (Poster, 1995; Turkle, 1995), the invention of new genders, or even genderless bodies (Plant, 2000, Wilding, 1998).

If the proponents of cyber liberation are correct and the internet is a utopia of endless possibility for storytelling and self-narration, the extensive use of this medium would, compared to offline media, facilitate a broadening of the range of stories about breast cancer experiences (Pitts, 2004). A few studies have evaluated the considerations of these liberation theorists with respect to online stories on breast cancer. Victoria Pitts (2004), in her study on traditional homepages and email lists, claims that women "do make visible [...] the painful and difficult aspects of breast cancer" (39). Yet they do not engage in "gender-play" (55), but rather "circulate conventional messages of [...] femininity" (39). Shani Orgad (2005), in her study on forums and discussion boards, concludes that, indeed, women with breast cancer do not articulate non-normative femininity. In another way, however, they do play with dominant gender roles online, namely through making visible the painful aspects of the illness. Public, online interaction about treatment possibilities and dealing with breast cancer enables women patients "to enter into a dialog where the dominant (doctors, and the medical authorities more generally, which are predominantly male) can no longer systematically silence these [women patient] voices" (Orgad, 2005, 159).

Orgad's and Pitts' pertinent studies do not yet address breast cancer writing in blogs. Existing studies on breast cancer experiences in weblogs, by contrast, are predominantly quantitative, not taking into account storytelling as a means of sense-making (Chung & Kim, 2008; Keim-Malpass

& Steeves, 2012; Meric et al., 2002). Adhering to literature on personal weblogs in general and illness weblogs in particular (Hardey, 2002; Heilferty, 2009; McCosker, 2008; Page, 2008), this paper argues that blogs represent a distinct and particular space for online storytelling of breast cancer. Blogs, thus, require their own study.

What, then, are blogs? Personal blogs are a collection of multi-media entries or small stories ('posts'), similar to an ongoing diary or commentary, written by an individual and published on a self-designed, open access, interactive Web page. On blogs, bloggers 'log' their on-going personal daily experiences online through using both text and audio-visual material. Their multi-media posts are archived in a reverse chronological order (Hardey, 2002; Page, 2008). Bloggers are able to rewrite their archived stories, often without a record of the changes made (McCosker, 2008). Furthermore, while weblogs are very personal, they are also open access and even welcome interaction with their audience through a guestbook or chat room (Heilferty, 2009). Given these particular and distinct features of blogging, the analysis of breast cancer blogs opens up new possibilities for gaining insight into how women tell their illness stories online and give meaning to themselves and their bodies.

Method and approach

Since this study aims to understand the ways in which women with breast cancer narrate themselves, their lives and their bodies through blogging we have chosen to conduct a qualitative, narrative approach that focuses on subjective experience. The first author sampled and analyzed thirteen Dutch-language personal weblogs of women with breast cancer. Initially, three weblogs were selected through using the search engine Google (translated Dutch search terms: 'weblog + breast cancer'). The other ten weblogs were found by clicking on links to other weblogs featured on the first three weblogs (virtual snowballing). Weblogs were selected in the sampling process that contained a significant amount of posts (twenty or more).

Almost all the sampled bloggers started blogging at the time of their diagnosis. Some of them were recently diagnosed and just started blogging. Others started blogging a while ago and had left the process of treatment behind them. All the bloggers underwent major invasive and disfiguring treatment, such as radiotherapy, chemotherapy, mastectomy or the removal of the lymph nodes. Most were still regularly updating their weblogs, generally once or twice a week. Some weblogs seem to have stopped. These women's posts vary in length: some are very lengthy (more than 600 words and multiple pictures), others brief (several sentences and few pictures) or even empty (no words at all and no pictures). Consequently, the sample of thirteen weblogs consists out of thousands of pages of visual and textual materials.

The first author read the sampled blogs and broadly analyzed emergent themes and storylines. However, as the preliminary analysis of the thirteen blogs contained too much material for in depth analysis, a representative smaller sample out of the bigger sample was selected. The smaller sample was formed on the basis of six identified features that significantly shaped the blogged stories within the larger sample: (1) stage of the illness experience at the moment of

selection, (2) age of the bloggers at the moment of selection, (3) level of professionalism, (4) design of the weblog, (5) level of intimacy with readers and (6) scope of the weblogs. Eventually, five weblogs were selected for adequately representing the variety within these features. In this way, a heterogeneous smaller sample was formed. The smaller sample included the following blogs: (1) 'Good tits, Bad tits' by Jeanette, (2) 'Just standing still' by Lucretia, (3) 'Ingeborg here and now' by Ingeborg, (4) 'I write, therefore I am' by Karin, and (5) 'Bosom blues' by Cancer Chick (see table A in the appendix for a summary of the five sampled weblogs on the basis of the six central features of the larger sample).²

The selected five blogs were followed by the first author on a monthly basis for a year (February 2012–February 2013) in order to capture changes and additions made to the weblogs. Using the encoding software NVivo 9, both the visual and textual contents of this sample were analyzed and interpreted. Emergent themes and storylines of the breast cancer experience were identified in consultation with the other author of the article. This resulted in four different types of self-narration by these women.

Four different types of self-narration

Our analysis of the five selected blogs identified four different types of narrating the self. While narrating, webbloggers configure themselves in different dramatis personae, namely as Estranged Cancer Patient (§1), as Transient (§2), as Heroic Survivor (§3) and as Disfigured Woman/Girl (§4).³ The Estranged Cancer Patient deals with the disruption of these blogging women's normal understanding of themselves and their body as result of the diagnosis and treatment. Women who narrate themselves as Transients get ready to change from stories of disturbance and disruption toward a more coherent and new type of self-narration. The Heroic Survivor signifies a particular reconfiguring of the self, namely toward an understanding of the self as returning to normalcy or as victorious. Finally, performing the Disfigured Woman/Girl means to act out a certain threat to their feminine, even girlish identity crucial for their breast cancer experience.⁴ Although several of these characteristics can also be found in other media, here we will focus solely on distinguishable and specific aspects of *blogged* breast cancer self-narrations.

Even if we analytically distinguish different types of self-narration, these should not be considered as separate narrations. In reality, they are interrelated. To some extent, they are associated with particular stages of the physical illness experience. For instance, the Estranged Cancer Patient predominantly acts in the stage of treatment, whereas the Disfigured Woman/Girl may enter after treatment when reflecting on mutilating sequelae of it. After scars begin to heal and one gets used to one's altered body, the Transient or Heroic Survivor may make their appearance. It is important to note, however, that the stage of the illness experience does not entirely determine the way these women narrate themselves. In fact, *all* types of self-narration can be at stake at *every* stage of the physical illness process: sometimes the chronology is reversed and sometimes (parts of) these self-narrations intermingle and overlap in alternative, paradoxical and surprising ways.

§1 Staging of the Estranged Cancer Patient

A breast cancer diagnosis is an immense shock in the sense that one is suddenly confronted with an uncertain future: the possibility of severe sickness, hospitalization, a trajectory of invasive treatments with horrible side-effects, and the threat of an untimely death. It is hardly surprising that breast cancer bloggers exhibit shock. Features of the Estranged Cancer Patients include more generally known modes of disturbances that produce a sense of alienation and estrangement from themselves, their lives and bodies, such as a sense of loss of control, feeling betrayed by their bodies, a unrecognizable mirror image and their being reduced to a medical object. In the following, however, we will focus on aspects of these women's storytelling characteristic for blogging: a break with their past and future and their muteness.

Temporal rupture

All women diagnosed with breast cancer refer to a drastic break with both their effectively healthy, unblemished lived past and their imagined and anticipated healthy future. This experience echoes itself in histories, hopes and expectations that some women see as no longer 'theirs' anymore. Ingeborg, for example, writes about herself in the third person when she recounts her life before breast cancer. Other women temper their expectations of their future or even delete all previously made references to their past in their previous blog posts. They literally rewrite their past, something blogging explicitly allows for. As former articulations of past and future lose their meaning and ultimately disappear from their storytelling, all these women seem to be left with is narrating their present life with cancer. In this context, women often use the metaphor of 'being stuck in time'. Lucretia's blog title "Just standing still" speaks volumes.

Muteness

It seems that these women's ultimate estrangement from their past and present lives and bodies is not articulated through (*rewritten*) words, but through *muteness and blankness*. Just after diagnoses, Jeanette updates her weblog with empty posts. Later on she recounts:

"I was not able to put my feelings into words; I lost 'my story'. I did not even know what I was feeling let alone that I was able to share it with you. I am literally afraid of dying and this [the empty posts] was the only way to let you know how I was doing..." (Jeanette)

Jeanette's words show that the overwhelming experience of one's advanced death as an actual possibility and a threat, results in muteness. Jeanette, rather paradoxically, articulates her 'chaos story' through a wordless story; with empty posts as silent screams of frustration. These kinds of stories are difficult to vocalize because of the inability to narrate. At the same time, they are difficult for others to listen to, which adds to the difficulty of telling them. This becomes apparent in Jeanette's words:

"About *that* [fear of death] you cannot talk in the human world, *there* you have to adjust to the common denominator. Here on *my* blog I write what I feel and how it storms in my head. I am literally scared to death! And if

you don't want to read about that, then you won't come to my blog anymore?!" (Jeanette)

This quote shows that for Jeanette it seems easier – although still very difficult – to recount her story of mortal fear on her blogs, rather than in real life. In a way that is seemingly impossible otherwise, Jeanette claims this public blog-space as distinctively 'hers': an environment in which she plays only by 'her' rules.

These examples of rewriting temporality and the posting of empty posts is interesting in light of Frank's argument that the ultimate cancerous experience can only take on the form of an "anti-narrative" (Frank, 1995, 98). Frank understands narratives as meaning-shapers, in that they assemble a coherent sequence of timing, events and experience. In the midst of the overwhelming experience of having (had) cancer, however, these women's formerly ordered temporal narratives no longer suffice and are thus therapeutically rewritten. Time, so it seems, becomes incoherent; it can even disappear in the sense that there is sometimes the experience of having no meaningful time left – no past, no future, and only a false presence. Consequently, there can only be an absence of telling and speaking: an anti-narrative. Our analysis shows that blogs offer the paradoxical possibility to narrate the anti-narrative by telling what cannot be told through the posting of an empty story.

§2 Interlude of the Transient

At some point while narrating themselves as Estranged Cancer Patients, almost all women carefully present themselves within a discourse of 'getting better'. This anticipation of a passage to survival and of narrating oneself as a Heroic Survivor, however, is still grounded in doubt and often manifests itself through certain (forswearing) rituals in order to deal with that uncertainty. Jeanette, for instance, is afraid of 'jinxing' her hopes for a healthier future by writing too much about them. Paradoxically, as hopes and expectations become meaningful again, they still may not be included in these women's stories.

These women's doubts of having a brighter future only seems to diminish when their physical state is improving (i.e. disappearing nausea, hair growing back or scars that heal) or when the end of their treatment or hospital visits is in sight. As Transients, these women disengage from the estranged life of a cancer patient and take on the passage to a more coherent and new type of narrating the self. Old narrations of estrangement and disturbance do not apply anymore, and new ways of understanding oneself have to be developed. This transition is often ritualized: it is marked by a defining symbolic (online or offline) moment – a rite of passage – in which these women consciously adapt and change in order to fit their new ways of understanding themselves. Some women's rite of passage takes shape through a change of design, tone or content of their blog – having more colors or cute pictures of daily life – thus embracing the regained lightness and normality of life.

A transition is not always effortless or comfortable though. A while after finishing treatment, Lucretia changes her blog icon from an angel of death into a butterfly. This change goes hand in hand with extensive meditation whether this is the

right symbol for her. After changing it back two times, she finally decides to go for the butterfly, while commenting:

“I may all sound too childish, but lately I feel so lost! Hopefully the butterfly [standing for being able to fly away from the cancerous experience] is not too optimistic.” (Lucretia)

At this point in her blog, it appears that Lucretia's old blog style, does not fit her altered (and long hoped for) way of understanding herself anymore. This change of heart – and consequently of blog style – surely may result in feelings of desperation and even anxiety.

After these transition rites, women who have (had) breast cancer narrate themselves differently. They give new meaning to themselves and their bodies again. In the form of narrating, this change is marked by a shift from silence or fragmentation to more coherent storytelling. For the narrator – and concurrently the chief character of the story – it mainly means a shift from chaos to control. For example, in the midst of dealing with her diagnosis, mastectomy and adjuvant treatment, Lucretia's writings are marked by unfinished sentences and phrases followed by three or more dots. Sometime after treatment, however, her writing style begins to change: she formulates complete sentences followed by a full stop. Her former fragmented and uncertain story accordingly changes into a more coherent and confident one. Since it needs very little editorial interventions to publish something online, blogging provides an easily accessible space to write and constantly rework stories. It allows these women to articulate their experience in their own, sometimes surprising, unconventional and fragmented linguistic and visual way. Their (excessive) use of punctuations, their style of formulating (unfinished) sentences and their personalized design is something that might not be possible in more conventional media. It is within and through these reworked and restyled stories that these women find new ways to understand and give meaning to their 'new' selves.

§3 *The appearance of the Heroic Survivor*

The Heroic Survivor, who manifests herself through militaristic and 'happily ever after' discourse, involves a particular reconfiguration of the disruptive cancer experience: a configuration through which women attempt to 're-own' themselves, their bodies their past, present and future. This type of self-narration generally takes on three forms: (1) a return to familiar lived, bodily narratives, (2) a victorious battle story of success, improvement and enhancement and finally (3), a continuation, at least in part, of narrating the self as an Estranged Cancer Patient. The staging of the Heroic Survivor in its various forms is particularly linked to the fact that blogging takes place in the public space, which facilitates sharing stories and connecting with one another.

Return to normality

At a certain point in their storytelling some women succeed in returning to the familiar embodied experience before the breast cancer. They refer to their lives and bodies as looking, feeling and acting as their own *again*. Cancer Chick, for example, gains weight because of her medication.

She feels capable again only after following a strict 1000 kcal diet. Against doctor's advice, she starts with this regime after cheering comments by readers of her blog about the effectiveness of this diet. Interestingly, shortly after stating that she re-gained her slim body Cancer Chick stops updating her weblog. After a few weeks of silence she briefly notes:

“You often hear of songwriters that they write their best songs if they are unhappy, well, I finally get what they mean by that. Being happy is great, however, it does not give you a lot of inspiration to write big literary pieces. The muse rather chooses her hosts among the ones that hang somewhere in the emotional gutter. Thus: finally it is a good sign that I write less.” (Cancer Chick)

In contrast to the muteness of the Estranged Cancer Patient, the re-gained *ability* to understand and give meaning to one's life leads Cancer Chick to stop writing. Here, it seems that the therapeutic exercise to write and re-write her story and share it with others in order to give (new) meaning to her life turns out to be successful and thus the need to update her blog diminishes.

Improvement

Other women's cancer experience is transformed into a battle story and, consequently, they seem to perceive their survival as a triumph, telling stories of success, progress and enhancement. They do not feel they are their own *again*: they narrate themselves as an *improved* and *better* 'me'. For example, some women experience their bodies as more capable than ever because their bodies are capable of defeating a lethal disease. Others consider the appearance of their scarred bodies as having surplus value: their scars reflect the battle they have fought and won. Yet others emphasize their new-found wisdom by explicitly sharing it with others, in this case, on their blogs. Karin states:

“And did you know that more women die from breast cancer than from lung cancer? It is a true battlefield. [Now that I know that], I warn all my friends to check their breasts regularly. And damn, I already saved the life of an acquaintance. [...] So ladies, [referring to the readers of her blogs] let's check those breasts!” (Karin)

By taking up the role as a 'guide' and sharing her knowledge as a Survivor, Karin's status as a Hero is affirmed. Not only did she save herself in the “true battlefield”, in turn, she also saves others from entering it in the first place.

Continuation of estrangement

While developing and re-developing their happy-ending stories of returning to normality or improvement, these women nevertheless continue to narrate themselves – at least in part – as Estranged Cancer Patients. Cancer Chick captures this complicated situation by writing:

“Most of the time I quite nicely succeed in adjusting my life to all the new small and big discomforts that this disease brings. [...] At least: I would think so. Because this remains the most difficult thing to the treacherous disease that is cancer: you never *know* for sure whether your body from the inside is as good as it looks from the outside...

People ask me: “You are cured now right?”, while they draw out the preferred answer by already fiercely nodding their heads. It is always a painful moment when I, against their expectations and sighs, carefully say “no.” (Cancer Chick)

Cancer Chick describes the impossibility of definitely closing the breast cancer chapter of her life because of the incessant uncertainty that is part and parcel of the experience of this particular disease. Although she may look healthy, her body may – still or again – hide the cancer. Her narration can be read as a refusal to divert one's own and other people's fear that this lethal disease can never be overcome completely.

For other breast cancer bloggers, it is not so much the fear of metastasis and dying that keeps on nagging. Rather, the continued pains and discomforts are still bothering them. Lucretia writes:

“All the five of us [fellow sufferers she met on her blog] have learned to live with painful joints, hot flushes with beads of sweat dripping down the spine to the butt crack and sudden windiness. At home this weird body is sometimes unpleasant and shameful, in this company, almost liberating.” (Lucretia)

Within the online community of breast cancer patients and survivors, so it seems, everybody is physically deviant. Because of that, these women share their stories without shame or having the feeling that they stir up fear or awkwardness in others.

The Heroic Survivor type discloses yet another co-determining aspect of blogging. Blogs elaborate new social relations and networks of support that offer information about breast cancer, much of which is divergent to medical knowledge by addressing (inter)personal issues of the breast cancer experience (see also: [Orgad, 2005](#)). Women's self-narrations are molded through these relations, networks and information systems. In the midst of online fellow sufferers who have similar stories, women like Lucretia do not feel like strangers anymore. Or by sharing their survival experience and skills online, more experienced women like Karin or the readers of Cancer Chick's blog help less experienced women to picture a bright(er) future – something they often cannot see by themselves – and work toward it. These results are interesting in light of Sherry Turkle's recent book 'Alone Together' (2011), in which she revises her 1990s optimism about the Net. In the end she argues that the Net does not offer us helpful self-constructions but only leaves us with shallow connections and ties that do not bind but only preoccupy. In essence, she claims, we are “alone together” on the Net ([Turkle, 2011, 1](#)). Our analysis of the Heroic survivor's staging suggests, however, that the Net and blogs in particular can actually connect women. It contradicts Turkle's view that on the Net a real “sense of being connected to [an] other human narrative” cannot exist (2011, 282).

§4 Acting out the Disfigured Woman/Girl

For most women who have (had) breast cancer, it is not only the cancerous illness experience – being diagnosed with a lethal disease and becoming a patient – that is disruptive. Their feminine identity is also at stake. Treatments such as

mastectomy, lumpectomy, removal of lymph nodes and loss of hairs and nails, implicitly or explicitly, affect aspect body parts and aspects of their lives invested with their sense of femininity. The Disfigured Woman/Girl, then, crucially involves a disturbed sense of femininity. Seemingly paradoxically, many bloggers narrate themselves as deviating from a stereotypical feminine norm or ideal (*Disfigured Woman/Girl*) while affirming this very norm (*Disfigured Woman/Girl*) through using their blog like an embodied avatar. An explicit affirmation of ruling norms of female embodiment, surely, can also function as a strategy to re-gain one's lost sense of femininity.

Addressing their deviating, masectomized body, the sampled women simultaneously affirm stereotypical femininity. In describing their failure to live up to specific feminine roles and activities (i.e. being caring) or looks (i.e. being breasted), they emphasize their importance and value. Typically, nearly all women visually construct their blogs in a way that strongly adheres to a feminine stereotype. They design their blogs using traditionally feminine colors (i.e. pink or pastel shades), dressing it up with pictures of cuddly toys, hearts, sparkles and angels. Lucretia – who says she has a hard time dealing with her unbreasted appearance, something that makes her feel (in her words) “de-feminized” – writes on her blog:

“That blog.. oh well... is something like the liberation from the limitations of my actual [masectomized] body. Here, I can be whoever I want to be! [...] It [the design of her blog] fits me.” (Lucretia)

Lucretia's use of cute album-like pictures and soft pastel colors on her blog can be interpreted as an act of portraying herself as a feminine woman on her blog, something she cannot do in the real world because of the “limitations” of her 'offline', masectomized body.

From the abundant use of girlish symbolism and the many stereotypical stories in these blogs, these women seem to reassert a sense of conventional femininity or youth, or even a childish innocence that is endangered by the cultural construction of mutilating breast cancer. These women's practice of decorating their blogs with visually striking images may be interpreted as an attempt to *appropriate* their disfigured, de-feminized bodies. When successful, they seem to virtually compensate for their offline loss of bodily feminine markers. As such, their online spaces can be understood as *incorporated*: blogs are in themselves a construction of new and complementing or extending, avatar-like bodies. Breast cancer bloggers' Internet spaces are thus not disembodied, as [Turkle \(1995\)](#) and other 1990s feminist Internet theorists argue, and do not only echo or exaggerate *offline embodiment*, like [Pitts empirical study shows \(Pitts, 2004\)](#). By using visual material, these women seem to construct new and ideal bodies, an ideal that they can, in fact, no longer epitomize with their offline bodies.

There are, however, exceptions to the dynamic between the experience of being deviant from a stereotypical norm and the quest to reassert this ideal through avatar-like blogs. Within certain contexts this ideal is not that persistent, which enables the emergence of new ways of giving meaning to their changed bodies. Some women use their blogs as a place – a podium even – where they do not feel the need to

live up to a dominant norm and actively display their altered, non-normative bodies. Jeanette, for example, repeatedly posts pictures of her bald head and mastectomized body, accompanied with texts like:

“THIS is my body. Behold it”. (Jeanette)

Jeanette's words show that in specific contexts, alternative ways of giving meaning to her deviant body become possible. On her blog, she seems to re-own her body: claiming that “THIS” body is “my body”. By displaying her blemished body on her blogs she, simultaneously, challenges the stigmatization and invisibility of mastectomized and bald female bodies.

This display of ‘deviant perceptibility’ challenges Goffman's claim that we tend to normalize “spoiled [i.e. deviant] identities” by taking up the role of – in this case – an ordinary feminine and healthy woman (Goffman, 1963, 31). For indeed, Jeanette and other bloggers in different stages of their breast cancer narratives explicitly claim their de-feminized and sick identity online. They seem to be able to do so because they regard, as Jeanette does, their blogs as distinctively ‘theirs’. The podium of the blog is thus not only ruled by mainstream norms as Goffman might argue, but allows these women a stage in which they can play by their own rules.

Conclusions

From our findings we can draw three conclusions: (1) the progression of the four different types of self-narration by women with breast cancer can be understood as a particular process of sense making, namely from feeling alienated to re-owning and re-appropriating themselves while a sense of alienation still lingers. (2) This particular process turns out to be influenced and co-determined by the specificity of blogs as a medium. (3) It still remains to be seen, however, whether this mediation reinforces greater freedom in defining oneself, as the feminist liberation scholars of the 1990s like to believe.

Process of self-narration

Each type of self-narration we have identified in our analysis illustrates that breast cancer diagnosis calls for new ways of relating and giving meaning to selves, lives and bodies. They involve a *particular* sense-making process: from alienation to appropriation with lingering alienation. While narrating themselves as Estranged Cancer Patients or *Disfigured Women/Girls*, women who have (had) breast cancer describe and articulate – often in fragmented ways – the overwhelming and drastically altering events they are confronted with. As a result, they do not experience their lives and bodies as fully owned anymore.

At a certain moment in their storytelling, however, some of these women's self-narrations begin to change. As Transients, they perform rites of passage within and through which they configure and reconfigure their fragmented stories of alienation into a more coherent story of renewed engagement with their selves, lives and bodies: a story that allows them to re-appropriate and re-inhabit these selves, lives and bodies. Here, these women begin to narrate themselves as Heroic Survivors or *Disfigured Women/Girls*. Generally they do so by affirming conventional norms and ideologies of femininity (i.e. being breastfed and caring) and being sick (i.e. temporally being

sick). Yet in certain contexts these women find alternative and surprising norms to adhere to while trying to appropriate themselves. If they succeed in these attempts, they are able to recognize and acknowledge, or even accept and welcome their bodies and lives ‘as their own’, again or anew.

Fuelled by continuous uncertainty, anxiety, discomfort, pain and by feeling mutilated and sometimes ‘de-feminized’, these women's process of appropriation is still marked by fragmentation in the narrative. Unfolding their stories toward possible Heroic Survivorship and/or Womanhood/Girliness, they often continue to narrate themselves, at least in part, as Estranged Cancer Patients or as Disfigured. Hence, this process of sense making as re-appropriation through different types of self-narration is an ongoing, non-linear, and never definite one. These women's self-narrations do not constitute a univocal journey toward coherence and appropriation but rather allow fragmentation and multiplicities of illness experiences to hold sway.

The medium is the message

As already indicated above, these women's process of sense making is influenced and co-determined by several aspects of weblogs. Similar to Sadie Plant's (2000) and Dennis Waskul et al.'s (2000) celebrated aspect of the Internet – its reversibility – blogs offer the possibility of always adding stories and changing existing ones. This facilitates breast cancer bloggers' therapeutic exercise of constantly writing and re-writing old and new stories and self-narrations. Weblogs, thus, allow for active and dynamic, continuous and drastic attunements of understanding one's life, self and body through the shaping and re-shaping of one's (autobiographical) stories.

Another aspect of blogging that influences self-narration is that it allows these women to publish their experience of having (had) breast cancer in a direct, perhaps unthinkingly, un-reflected way, culminating in surprising and unconventional self-narrations. These women appear to ‘blog’ with minimal editorial intervention, when and where it suits them. This emphasizes the personalized dimension of blogging (“my blog”) and a heightened degree of control these women feel they have over the (unedited) *content*, (unpolished) *linguistic style* and *visual design* of the online representations of their experience (see also: Orgad, 2005). We have seen that women sometimes articulate their (continuing) alienating illness experience online in a manner that seems to be impossible, these women argue, in the offline ‘real’ world. Other women use linguistic and semantic styles (punctuation, unfinished sentences, wordless stories, etc.) that may not be possible in other media. Further, these women use the visual potential of blogs to (co-) shape their stories, and even more, themselves and their (extending) bodies.

Finally, the blogosphere offers these women meaningful new relations with fellow sufferers, and thereby influences their stories in a number of ways. By sharing their stories on their blogs they are able to help each other in decision-making processes, or through the online contact with partners in misfortune they do not feel like strangers anymore.

In sum, the classical statement of Marshall McLuhan is of significance in this study: “the medium is the message” (McLuhan, 1964, 7). Indeed, the possibilities of blogging as a medium and breast cancer bloggers' self-narrations are symbiotically related to one another.

Blogosphere: a disenchanting utopia or a paradise of chaos?

Our findings lead us to question *on which terms* these women voice their experience, and thus whether blogging actually achieves its widely professed liberation. Whereas cyberspace and specifically the blogosphere has been welcomed by some as a feminist utopia of free selves and free (of) bodies (Beetham, 2006; Plant, 2000; Turkle, 1995; Wilding, 1998), our analysis shows that blogs cannot be understood as a neutral, disembodied territory in which women define themselves absent from dominant and restrictive offline, embodied culture. The blogosphere must be seen as an embodied space where – in characteristic and manifold ways – dominant, stereotypical and normative definitions of situations, bodies and selves are generally affirmed and sometimes contested.

Whereas the jubilation of the cyber liberation movement should be tempered, there are still reasons for celebrating the online genre of breast cancer autobiographies for its emancipatory, liberating potential. In line with studies that explore how women can create and develop emancipatory relations and bonds on the internet (Sundén, 2001; Plant, 2000), our study reveals that sharing experiences through blogging supports women to acknowledge their non-normative, deviant bodies as their own. They are also encouraged to complement and even challenge medical authority and its dominant (mostly male) doctor – (in this case female) patient relationship through the availability of alternative (non-medical) knowledge systems within these weblogs (see also: Orgad, 2005). The abovementioned aspects of blogging that enable and even encourage women to articulate fragmented and unconventional stories of (continued) disturbance and alienation can also be understood as emancipatory and liberating.

Since these kinds of chaos stories (Frank, 1995) do not resound with the modernist quest to overcome one's illness they signify a process of appropriation that *retains* continued alienation. This process can be understood as a postmodern act of resistance, or in Goffmanian fashion, as the claiming of “spoiled identities” (Goffman, 1963, 31). Although these women thus still tend to generally affirm gender stereotypicality and (modernist) normativity of being sick, by blogging and engaging with other bloggers they also acknowledge and even welcome multiple, fragmented, non-cohesive and non-normative illness experiences and self-narrations.

Through writing and re-writing their stories on the Internet, women with breast cancer narrate themselves as Estranged Cancer Patients, as Transients, as Heroic Survivors or as Disfigured Women/Girls. The progression of these women's self-narrations are read as a process of defining their new and altered selves ‘as themselves’ – albeit always temporary and never absolute – something they do – however difficult and incompletely – on their own blogged terms. In this sense, these breast cancer blogger's experiences echo Lorde's autobiographical writings as quoted in the introduction of this paper: “I did not feel the same [...] But I still felt like myself” (Lorde, 1980, 49).

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Appendix 1. Table A: summary of the five sampled weblogs on the basis of the six central features of the larger sample

	Lucretia	Karin	Ingeborg	Jeanette	Cancer Chick
Illness stage	Upon diagnoses	>5 years after treatment	3 yr. after treatment	During treatment	1.5 yrs. after treatment
Age	±60	±55	±40	45	33
Professionalism	Amateur	A professional writer before starting the weblog	Amateur	Amateur	Started writing professionally after starting the weblog
Design	Many pictures and colors	Black-and-white blog, emphasis on text, one picture per post	Some pictures and many colors	Many pictures and colors	Some pictures and many colors
Intimacy	Very personal but also a lot of references to medical facts	Analyzing personal experiences in light of broader socio-cultural debates	Very personal	Very personal	Very personal
Scope	Only breast cancer	Covering also many other subjects	Only breast cancer	Only breast cancer	Only breast cancer

Endnotes

¹ Breast cancer is not an exclusive female disease. Male breast cancer accounts for around 1% of all breast cancer cases. This study, however, solely focuses on breast cancer in women.

² The blog titles and the quoted texts are translated from Dutch by the first author of this article. In the paper, these women's self-chosen blog names are used in order to refer to the different bloggers and blogs.

³ Drawing upon literature on narrative analysis, these dramatis personae should not be equated with different coping strategies and should not be read as psychological adjustment.

⁴ Due to the limited scope of the paper (i.e. *online* spaces of storytelling and self-definition), this study is not an evaluation of how breast cancer

bloggers *actually* experience and deal with having (had) breast cancer. This analysis only focuses on how they *narrate* themselves, their lives and bodies *online*. Further projects should advance the study of the interplay and relation between online self-narration and actual, offline sense making by these women.

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