

Doing Illness

Cancer Narratives in Digital Media

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Through three case studies, the article explores how digital media have been used in recent years to depict and comprehend experiences of cancer. It first investigates the illness blog, specifically Swedish journalist and musician Kristian Gidlund's immensely popular blog In My Body, in which he, from 2011 to 2013, shared the narrative of his struggle with an aggressive, incurable, and ultimately deadly stomach cancer. It continues by discussing Italian engineer, artist, and hacker Salvatore Iaconesi's digital open-source project La Cura – The Cure (2012), which has great relevance from both the digital and the medical humanities perspectives in the way Iaconesi uses his personal narrative of brain cancer to encourage people to join his struggle to find a cure. Finally, it analyzes the American couple Ryan and Amy Green's videogame That Dragon, Cancer (2016). A game differing significantly from video and computer games in general and from other games taking cancer as their subject by letting the player enter the role of caregiver to a small child dying of cancer. Expanding on Lisa Diedrich's theoretical concept of "doing illness", the article emphasizes the performative dimension of narrating illness in digital media, considering how these authors and creators negotiate with narrative, cultural, and medial scripts when portraying their cancer experiences. It highlights the interactive and participatory dimension of doing illness in digital media, by exploring how the blog, open-source project, and videogame

both invite and limit the audience's opportunities to interact and participate with the illness narrative conveyed.

Introduction

"*Illness calls for stories*", Arthur Frank (1995) states in his by the now-classic book on illness, *The Wounded Storyteller* (p. 54). Although these words were written at the beginning of the Internet era, they seem especially true today considering the vast number of biographically anchored illness narratives produced, distributed, and consumed via digital media in recent years. From a media perspective, however, research into pathographies and autopathographies – that is, biographical and autobiographical narratives of illness (Couser, 1997; Hawkins, 1999) – has tended to focus more or less on illness narratives conveyed by the medium of the book. As Tamar Tembeck (2017) points out, "*comparatively little research has focused on autopathographic practices beyond the literary world*" (p. 207), even though renowned scholars in the field, such as G. Thomas Couser (2009:13), have acknowledged the impact of digital media when it comes to the worldwide proliferation of illness narratives.

Against this background, the article seeks to broaden our perspective on illness narratives by acknowledging that they come in different forms and are conveyed by different media, a fact Stella Bolaki (2016) captures in the phrase constituting the main title of her book, *Illness as Many Narratives*. From this viewpoint, the conventionally printed book is to be regarded as a medium with its own affordances and constraints when it comes to narrating illness, although this is rarely noted in research. The same is, of course, true when it comes to the material in focus here: an illness blog, an open-source project, and a videogame. In short, the article presents an explorative study of how these specific digital media formats, or genres, are used to narrate the experience of being diagnosed with or living in the shadow of one of our most feared diseases: cancer.

This article begins by considering the illness blog, specifically, Swedish journalist and musician Kristian Gidlund's immensely popular blog *In My Body*, in which he, from 2011 to 2013, shared the narrative of his struggle with an aggressive form of incurable and ultimately deadly stomach cancer. Then I continue by discussing the Italian engineer, artist, and hacker Salvatore Iaconesi's digital open-source project *La Cura – The Cure*, from 2012, a project of great relevance from both the digital and medical humanities perspectives in the way Iaconesi uses

the personal narrative of a glioma in his brain to encourage people to be part of his struggle to find a cure. Finally, I consider the video game *That Dragon, Cancer*, released on January 2016. This game differs in significant ways from video and computer games in general and, in particular, from other types of games taking cancer as their subject by letting the player enter the role of caregiver to a small child dying of cancer.

These cases have been selected to exemplify the multifaceted ways digital media are used by people affected by cancer to narrate their experiences. However, the article does not provide an exhaustive account of how digital media are used for this purpose, nor is it the intention. The article does not consider how cancer is narrated in YouTube vlogs (Arduser, 2017; Hale, Gonzales & Richardson, 2018), status updates on Facebook (Stage, 2017), or online communities and networks depicting in more ordinary ways what living with cancer really means (Kennedy, 2016), to mention just a few examples.

From a methodological perspective, the article largely comprises a narrative analysis of the above-mentioned material. The focus is on the story expressed in the examined medial contexts, not least on how digital media both enables and limit a certain kind of storytelling. In this regard, I have been inspired by Lisa Diedrich's (2007) theoretical concept of 'doing illness' by which she emphasizes that narratives of illness involve a performative dimension, not being fixed, but in constant motion. According to her, they entail constant negotiation with narrative, social, and cultural scripts.

In the following, I expand on this idea by considering how the analyzed narratives also negotiate with medial scripts, with a focus on the possibility of the audience interacting with and participating in doing illness. In this, the audience should be understood both as an implied audience, that is, the studied authors and creators do illness in relation to preconceived images of the audience (cf. Schmidt, 2013), and as a concrete audience comprising the actual blog readers, contributors to the open-source project, and video game players. In digital media research, it is often argued that digital media distinguish themselves from analogue media by their potential for interaction and participation. One has talked about digital culture as a 'participatory culture' (Jenkins, 2006), in which audience members leave their passive role and become users, and hence are more active and freer to interact with and participate in relation to the content at hand (Brough, 2014; Bruns, 2008; Lind, 2015, 2012). As is evident in the following case studies, however, the invitation to interact and participate with the content takes different expressions

in the blog, open-source project, and video game, as does the actual interaction and participation.

Blogging the cancer experience

Kristian Gidlund launched the blog *In My Body* in March 2011 in reaction to his cancer diagnosis, which he described in the blog's first entry. This fact is itself congruent with the motives underlying most illness blogs on cancer and other life-threatening diseases. In short, these blogs could be regarded as a response to the trauma, or the biographical disruption of the sense of one's former self, caused by the diagnosis (cf. Bury, 1982; Conway, 2007; Diedrich, 2007).

The blog is a digital format often viewed as part of 'Web 2.0'. In short, it could be seen as a 'remediation' (Bolter & Grusin, 1999) of the traditional analogue diary, the main difference being its public nature and the reader's ability to read and directly interact with the personal narrative, more or less in real-time. Due to this fact, the blog has been viewed as particularly authentic, rendering life while it is going on (cf. McNeill, 2003, Rettberg, 2014, Sorapure, 2003).

Consequently, it is easy to understand the blog's appeal to those, like Gidlund, who suddenly face severe illness. On a formal level, Gidlund's blog can be seen as an example of a traditional illness blog. It was published using a pre-existing template provided by the blog-publishing service Blogger and it mainly comprises text entries concerning the experience of illness, occasionally illustrated with photos, which are presented in reverse chronological sequence (cf. Nesby & Salomonsen, 2016:46). While it was up and running, the blog's readers could comment on the entries using the built-in commenting feature.

In one important respect, however, Gidlund's blog distinguishes itself from blogs in general and from other illness blogs in particular, namely regarding the interactive dimension. From the outset, Gidlund insisted on the private nature of his blog in relation to the reader: "*This is a selfish blog. Created by myself. For myself. If you want to read it, you are free to do so. But this is my way of dealing with this situation*" (Gidlund, 2011, my translation). In line with this statement, Gidlund was consistent in not participating in the lively discussions that his blog entries prompted.

The explicit author-reader interactivity often seen as an important dimension of cancer and illness blogs (see Nesby & Salomonsen, 2016; Page, 2012), in which, the blog's function is to establish mutual communication between the ill person and a larger group of readers, is declined in Gidlund's case. Unlike the cancer blogs

Ruth E. Page (2012) investigates, Gidlund does not tell his story “*explicitly with the purpose of connecting with a community of users*” (p. 54), even though he expresses the awareness that he is writing for an audience whose scope he does not initially understand.

The blog’s readers seem to have been untroubled by Gidlund’s unwillingness to communicate with them in the comment field, or in other ways. On the contrary, many of the blog’s readers were from the very beginning eager to interact with the content uploaded. It is also clear, that, their comments expose the emotional involvement that this kind of blogging often evokes. The comments largely consist of greetings to Gidlund and wish for his quick recovery, together with advice on various treatments for cancer.

It is also striking that the more emotionally charged Gidlund’s entries are, the more comments they elicit. One of his last entries, for example, in which he declares that his narrative, and soon his life, has come to an end, elicited 1589 comments, compared with only 373 comments for the previous entry. This illustrates, how digital media formats such as blogs and Facebook generally encourage the production of emotionally charged stories to which readers can connect and respond (Garde-Hansen & Gorton, 2013).

Notable in the readers’ comments are their strong emotional involvement with Gidlund’s story. Many comments describe how, when reading, the commenter was physically moved to the extent that “*tears slowly fill [their] eyes*”, for example. In line with the Swedish cancer blogs analyzed by Yvonne Andersson (2007), the readers’ emotional involvement with Gidlund’s blog could also be exemplified by their sending “*strengthening hugs*” or the like (p. 13). It is evident, that the readers greatly valued the emotional experience of reading the blog, while the social value ascribed to the blog seems high. Gidlund’s confession that cancer affected his life in every possible way frequently prompted reader narratives about their own experiences as cancer patients or as relatives or friends of people living with the disease. This illustrates, how the blog, in sharp contrast to Gidlund’s statement that it is a ‘selfish blog’, functioned as a digital platform creating opportunities for his readers to expose their own personal struggles with cancer, making the disease into a collective shared experience.

In this regard, one could compare Gidlund’s blog to discussions taking place on internet discussion forums, and especially to what Page (2012) calls ‘second stories’, i.e. “*stories or story episodes that follow a narrative that has been told either immediately before, or in close proximity to, the turn that has preceded it*” (p. 30). She illustrates, the use of second stories by an episode of one person telling about witnessing an

accident, which evokes a similar story from the person listening. The same logic is to be found in Gidlund's blog. It is also evident, that the second stories, in this case, correspond well to the overall function of the second stories that Page highlights: that of being supportive and building solidarity.

In some cases, however, the second stories on Gidlund's blog become what Page (2012) calls "*face-threatening*" by "*adopting an opposing role*" (pp. 39, 41). More precisely, some blog readers dispute the authenticity of the blog and the truthfulness of Gidlund's depiction of his condition, as in the following example, which Gidlund himself cites in the blog: "*No one will miss you when you die. You just write to show how good you are. You are self-conscious. Everything you do is well thought out.*" (Gidlund, 2013a, my translation). In addition to exemplifying the negative side of sharing personal experiences on the Internet, the fact that Gidlund himself chooses to quote from this post shows that he, after all, reads the discussion in the comment field, even though he does not actively participate in it. Nevertheless, such critical comments should be considered exceptions confirming the rule. Most of the blog's readers did appreciate what they saw as Gidlund's authentic depiction of his fight against cancer, and besides the affecting content, they repeatedly emphasized the blog's aesthetic dimension: the fact that Gidlund is an accomplished writer, who succeeds in narrating what might be considered unnarratable. In other words, what makes Gidlund's blog really stand out in the readers' eyes is its artistic expression, which in turn makes it difficult to dismiss it negatively as non-art or so-called 'victim art', a fate encountered by many printed illness narratives in recent decades (cf. Diedrich, 2007; Jurecic, 2012).

The high aesthetic value ascribed to the blog, together with the massive media coverage that soon made Gidlund into a celebrity, probably explains why he was eventually contacted by Forum, one of Sweden's most renowned book publishers and part of the Bonnier media group, offering to publish the blog in book form. The fact that the blog was 'remediated' in this way into, not one but two, traditional printed books (Gidlund, 2013b, 2013c) further distinguish it from regular illness blogs published only in digital form.

The remediation of the blog into book form also illustrates, the affordances and constraints of these two media forms when it comes to representing the cancer experience. A significant medium-specific difference between the blog and the books concerns the interactive and participatory dimensions touched on above. While the blog reader could follow the cancer experience in real-time, as it was happening, the reader of the books read about the events at a safe distance after they had taken place. Like Gidlund himself, the blog's readers did not know where

the story would go next, and they could, as one reviewer wrote, “*keep pace with the author, hoping and despairing with him*” (Lindroth, 2013, my translation). The readers of the books, in contrast, take part in a story that has already been completed and moulded into a form that fits the book as a medium. Gone are the exact date indications of when blog entries were originally written; rather, in the books, the passage of time is marked by indications of the then-current month. The profound comments in the comment fields and the links to the music that forms a kind of a soundtrack to the blog are similarly absent. Retrospectively, the narrative conveyed in the book format also acquires a completely different dramaturgy, with a clear beginning, middle, and end, and with clearly marked turning points. The first when Gidlund is told that he is cured, and the second when he shortly thereafter receives notice that his cancer has returned and this time is incurable. As the same reviewer pointed out, this, together with the knowledge of Gidlund’s death, leads to a completely different reading experience coloured by “*powerlessness*” (Lindroth, 2013, my translation).

Interestingly, Gidlund himself self-reflexively comments in the blog about how he views these two media formats assigning them different functions. The blog is viewed in terms of therapy, associating it with the role writing often plays when it comes to illness narratives in general and illness blogging in particular (Gubar, 2016). The continuous writing performed in the blog, was a way for Gidlund to act as a writing subject, but also a way for him to communicate with the outside world, with friends and relatives, about what he was going through. The books, on the other hand, constitute a testament, “[a] *monument. My runestone in the fields. The street that bears my name*” (Gidlund, 2013b:329, my translation). This description actualizes a relatively traditional view of the printed book as a medium considered more persistent than the blog, a notion largely dependent on the fact that the book, like the runestone, is a material object. Despite emphasizing the digital blog’s positive therapeutic function, it is valued negatively by Gidlund. Due to its immateriality and volatility, the blog, in the long run, lacks the printed book’s long-term stability and memory-preserving potential. It is also the publishing of the two books that finally made it possible for Gidlund to transcend the status of an illness blogger and truly become the author that he had dreamt of being for so long. In many ways, it was his cancer that in the end elevated him into an acknowledged writer.

Exposing and crowdsourcing cancer

As in the case of Gidlund, where the blog and the books could be viewed more or less as responses to the existential limbo caused by the cancer diagnosis, Salvatore Iaconesi's project, *La Cura – The Cure*, could be viewed as his attempt to master the fact that he was diagnosed with brain cancer.

La Cura consisted of a website where Iaconesi (2012a) shared his hacked medical records and x-rays of his brain and the extensive social media network that soon accompanied it. The project began in September 2012 when Iaconesi, himself an artist, posted a video on YouTube entitled "*My Open Source Cure*". After declaring "*I have brain cancer*", he urged the viewers to participate in curing him:

"So what I ask is give me a cure. ... Use the data and information and digital images in open format which I published about my head condition ... to produce something ... to produce a video, a graphic, an artwork, a game, or maybe even to study the information to find a cure for me" (Iaconesi, 2012b).

This invitation to interact and to participate in this social media project stands in sharp contrast to how Gidlund in his blog self-consciously declined this same possibility. By means of this 'crowdsourcing' gesture, Iaconesi fully embraced the participatory and intercommunicative dimension of digital media. This is accentuated, if one considers Iaconesi's choice of media platform on which to share the narrative of his disease, YouTube, by that time considered to be the largest community-building video sharing site on the internet. At the same time, the fact that Iaconesi's project was based on the audience's willingness to participate underscores that it, strictly speaking, was not Iaconesi himself who was 'doing' illness. Instead, he had a more *curatorial* role as the one who, through sharing his illness narrative, spurred others to expand on it through their narratives and artworks and later curated them.

By hacking into and sharing his medical records openly on the Internet, which he afterwards described as easier said than done due to Italian patient rights legislation (Delfanti & Iaconesi, 2016: 127) Iaconesi actively resisted being objectified and reduced to the figure of 'the patient as text', in the words of Petter Aaslestad (2009). Instead, Iaconesi came to embody the patient-activist of the 'Health 2.0' movement in at least two ways: first, on a personal level, by trying to figure out how he should act vis-à-vis the treatment of his own brain cancer, by reaching out to actors other than the traditional medical authorities and, second, on a more ge-

neral level, by trying to raise awareness of cancer by not letting himself be defined by the medical gaze alone, widening the notion of what a cure could be. The project could be seen, as a kind of translation between the medical community with its views of cancer, and the notions of cancer flourishing in the culture at large.

La Cura was enormously successful. The website soon went viral and by 2014 Iaconesi had received more than one million responses to his illness narrative in the form of art pieces, audio recordings, stories, films, performances, text messages, and medical advice from all over the world (Delfanti & Iaconesi, 2016:132). Notable among the contributions are, for example graphic designer Alessandro Damini's image of a brain in the style of a classic advertisement for the Italian typewriter and computer manufacturer Olivetti, and artist Patrick Lichty's full-scale 3D sculpture of Iaconesi's brain (cf. Delfanti & Iaconesi, 2016:133; Stage, 2017:107).

La Cura soon developed into an extensive transmedial narrative (Jenkins, 2008) involving different media forms as well as different actors. Medical experts also participated in the project by sharing their advice as to the best medical treatments for Iaconesi's brain tumour. Through the contacts the project established between Iaconesi and brain surgeons from around the world, he finally managed to assemble a medical team that successfully removed the tumour and at least physically cured him of cancer. *La Cura* thus fundamentally differs from Gidlund's blog; while the latter was largely marked by a tragic plot, Iaconesi's project ended happily and can be viewed as having what Couser (1997:39) calls a comic plot or Frank (1995:115) 'a restitution narrative' that ultimately concerns the 'triumph of medicine'.

In light of the project as a whole, *La Cura* can be seen as one of many examples in which doing illness in digital media is used to negotiate the traditional view of the patient as passive (cf. Stage, 2017:106). Iaconesi himself emphasized in interviews throughout his experience that making his disease into an art project allowed him to remain the same amid the chaos of his cancer diagnosis. In other words, he insisted on 'biographical continuity' (Williams, 2000:61) instead of biographical disruption in the face of the disease: "*My personal purpose for this disclosure is to autonomously shape my own human condition. I have a disease but I am not a 'diseased person'. I am a person*" (Iaconesi cited by Lichty, 2012).

In *Networked Cancer* (2017), Carsten Stage uses *La Cura* to exemplify what he sees as a recent trend in narratives of illness, fostered by the development of new digital media. Stage's (2017) main argument in the book is that we are "*currently witnessing the rise of a new type of personal narrative-affective cancer practice on social media, which adds to the existing types of cancer narratives*" (p. 1). More precisely, Stage

(2017) calls this new practice an 'entrepreneurial cancer practice' (p. 1) characterized by cancer patients responding to their diagnosis and treatment by making the disease into a project using digital tools and infrastructure, primarily social media such as blogs, Facebook, and Twitter. They use these social media platforms positively, to make things happen, instead of letting themselves be paralyzed and devoured by their disease.

In a way, this entrepreneurial spirit could also be said to characterize Gidlund's blog. As mentioned above, it is his blogging about his cancer disease that ultimately makes him the author he always wanted to be. At the same time, Gidlund's blog fundamentally differs from the digital practices that Stage investigates by not explicitly using the personal cancer experience to raise money for cancer research or, as in the case of *La Cura*, to raise awareness of cancer overall. In Gidlund's case, this is more of a side effect than a stated goal.

Cancer and videogames

The independent video game *That Dragon, Cancer* could be regarded as more in line with Stage's conception of entrepreneurial cancer practice. Computer programmer Ryan Green created this game together with his wife Amy in response to the death of their five-year-old son Joel, who had been diagnosed with terminal cancer at the age of twelve months. In interviews and talks, and in the documentary *Thank You for Playing* (Osit & Zouhali-Worrall, 2015), they describe creating the game to commemorate Joel and to raise awareness of what it means to care for a deathly ill child. The game's entrepreneurial spirit is also highlighted by the fact that it was made possible by a Kickstarter crowdfunding campaign. This shows itself in the final version of the game, in which the Greens incorporated in the gameplay the voices of some of their financial supporters, in the form of letters and artworks concerning similar losses of close family or relatives. As in the case of *La Cura*, and to a lesser extent *In My Body*, this illustrates how doing cancer in *That Dragon, Cancer* goes beyond the personal level, opening up a collective dimension of cancer.

At the same time, it is evident that *That Dragon, Cancer* has a biographical anchoring, and as Couser (2017:380) has acknowledged, one could characterize it as a video game memoir. Throughout, the game uses authentic material such as recordings of Ryan and Amy's voices and of Joel's giggling, crying, and screaming. The game also ends by showing real pictures of Joel and his family. However, in

contrast to the other cases investigated here, *That Dragon, Cancer* does not center on narrating the cancer experience from the inside, from the perspective of the person living with the disease. What the game instead focuses on, is letting the player adopt the caregiver's perspective, although it is possible to occasionally switch roles, and experience the situation through, for example, Joel's eyes or from the perspective of the doctors, as in the scene where the Greens are told that Joel's cancer is incurable. The focus is constantly changing, giving a complex and multi-dimensional narrative about the cancer experience being rendered in the game. In this respect, the affordances of the video game medium could be said to be used to the utmost.

Otherwise, *That Dragon, Cancer* is a highly narrative game with a playing time of approximately two hours. It could be seen as an example of what Astrid Ensslin (2014) calls 'literary videogames', that is, "digital artefacts that combine so-called ludic (from Latin *ludus*: game or play), and literary (from Latin *littera*: alphabetic letters, or plural *litterae*, piece of writing) elements" (p. 1). *That Dragon, Cancer* consists of fourteen scenes or chapters in which the player is allowed to follow Joel's and his parent's journey from, to paraphrase Susan Sontag's (1978:3) famous words, 'the kingdom of the well' to 'the kingdom of the sick'. The narrative and literary qualities of the game are emphasized by the use of a strong narrative voice belonging foremost to Ryan Green and are further emphasized by text being scribbled down at the same time as the player is confronted with the story of Joel's fate. In turn, the ludic dimension of the narrative consists both of the fact that the player must explore the setting where the narrative takes place, and of the small mini-games drawing from a wide range of traditional video and computer game genres, that one must play through to advance in the game. For example, these mini-games concern controlling balloons so that they do not crash into threatening cancer cells, or navigating a Mario Kart-like hospital trolley through the hospital's corridors to collect points in the form of various medications and treatments.

On a graphic and stylistic level, the game gives a rather abstract impression (cf. Schott, 2017:6), and from the beginning, it clearly is not striving for realism. For example, it is impossible to discern the facial features of the characters in the game or to identify the setting. Like the characters, the setting is stripped of any obvious identity markers connecting it to a reality outside the game. However, from the player's perspective, the effect of these aesthetic choices is to allow the players truly to immerse themselves in the gameplay. It could be said that the game's abstract nature, especially when it comes to the characters, allows the players to adopt the caregiver role, which, as pointed out, is the *raison d'être* of the game.

Also, when it comes to the actual game moments, it is often difficult to know what one is expected to do as a player. Rather than seeing this as a fault in the game, one can interpret it as another way to make the player experience the feeling of being in a situation like the one the Greens had to live through, in which one simply does not know how to act. The gameplay largely builds on the player's active exploration of the various and often difficult situations s/he is presented with. In this regard, *That Dragon, Cancer* could more generally be said to adhere to the popular video game genre of the adventure video game or explorative game. Specifically, when it comes to illness narratives it could be said to adhere to Frank's (1995) description of the 'quest narrative' in which Joel's cancer diagnosis, at least from the player's perspective, "*is the occasion of a journey that becomes a quest*" (p. 115).

The game's adventure- and quest-like character does not imply that it urges the player to move forward quickly, which is the case in most commercial adventure games. On the contrary, when it comes to speed, *That Dragon, Cancer* could be compared to what Ensslin (2014) calls a 'slow game', forcing its player "*to proceed at an extremely slow pace, thus evoking a meditative mood*" (p. 142). As Ensslin (2014) points out, this design feature will "*give players breathing space and further exploratory options, to make them reflect on their actions*" (p. 142). A fact that in *That Dragon, Cancer* goes hand in hand with the aim of giving the player knowledge of what it means to care for a deathly ill child.

The game opens on a paradisiacal scene of Joel sitting by a lake feeding birds, while the second scene shows Joel playing in the playground. Both these introductory scenes express harmony and joy which is emphasized by the musical score of calm classical music. At the same time the disease lingers in the background, as becomes evident through the sound recordings of Ryan and Amy's discussions and Amy's voicemails. After these introductory scenes, the player gradually faces different situations the Greens confronted during Joel's short life; from the time of his cancer diagnosis to medical treatment and finally his death. The setting changes from the beautiful and brightly lit landscape, to the dark rendering of the hospital.

The famous Youtuber PewDiePie's playthrough clearly attests to the extent to which the game emotionally activates the player. With tears in his eyes, he exclaimed "*I can't play this! It's too much*", and after playing two-thirds of the game, he concluded: "*It was very, very heavy*" (PewDiePie, 2016). The enormous number of comments on the video (nearly 28,000) reporting the feelings of the viewers of PewDiePie playing the game underscores the emotional aspect of the game. The

fact that, *That Dragon, Cancer* manages to arouse the player's feelings to such an extent makes it part of a trend of so-called serious video games (Breuer & Bente, 2010) or knowledge games (Schrier, 2016) which let players get emotionally involved in what it means to live with a disease or, as is the case of the Greens, to be affected by it in other ways. In this regard, one could mention the example of Zoe Quinn's *Depression Quest* (2013), which lets the player experience living with depression from the inside. In doing so, *Depression Quest*, as stated on the website devoted to the game,

"aims to show other sufferers of depression that they are not alone in their feelings, and to illustrate to people who may not understand the illness the depths of what it can do to people" (Quinn, 2013).

While it could be argued, that *That Dragon, Cancer* on a general level is part of this broader video game trend it nevertheless stands out in comparison with other games taking cancer as their subject, such as *Remission 1* and *2*, created by Hope-lab, *"a social innovation lab focused on designing science-based technologies to improve the health and well-being of teens and young adults"* (Wikipedia). In these games, which are specially intended for players with a cancer diagnosis, the player controls a nano-robot that fights cancer cells inside cancer patients' bodies. As in a first-person shooter game, the player tries to defeat cancer using various weapons such as chemotherapy, radiation, and antibiotics. The *Remission* series strongly adheres to a view of cancer as an enemy to be defeated and it reproduces the conceptual understanding of the cancer patient as involved in a war on cancer that Susan Sontag had already critiqued in the 1970s in her famous book *Illness as Metaphor* (1978).

In *That Dragon, Cancer*, this war is in a way lost beforehand. There is no victorious ending, no comic plot. From the beginning, not least from the paratextual elements (Genette, 1997) surrounding the game, the player is aware of its outcome: Joel's inevitable death. As hinted at above, and emphasized by Gareth Schott (2017), this knowledge removes the *"desire to advance as efficiently and quickly as possible"* (p. 7). Thus, this game works against the logics of most computer and video games, the goal of which is often to proceed as quickly as possible from one challenge to another. As a player of *That Dragon, Cancer*, one simply wants to postpone the inevitable and let Joel live a little bit longer.

Conclusion

Let us conclude by returning to Arthur Frank's (1995) statement: "*Illness calls for stories*" (p. 54). As this exploratory study of the use of digital media to narrate experiences of cancer shows, digital media have opened up for many ways to answer this call, from blogs to digital open-source projects and video games. And, as stated in the introduction, one could easily expand the palette of digital illness narratives by, for example, considering the sharing of illness narratives about cancer in social media, on Facebook, Twitter, and YouTube.

One thing that becomes especially evident in the analyzed material, is how doing illness in digital media concerns various relationships with an implied or real audience. The most striking aspect is how Gidlund, Iaconesi and the Greens, in different ways, work both with and against their digital medium, regarding the matter of interaction and participation. From the viewpoint of the audience, the blog, open-source project, and video game arguably constitute different participatory cultures. In this regard, *La Cura* stands out by fully embracing the interactive and participatory potential of digital media. In its entirety, it was dependent on the audience and its willingness to involve itself in co-creation. There was also from the beginning an explicit ambition from Iaconesi's side to make his personal experience of disease into a collective concern. One prerequisite for the project was, that after disclosing his personal narrative of illness on YouTube, he chose to abandon his authorial control over what the audience would do with it, assuming a curatorial role instead. *La Cura* in a fundamental way resembles the fan cultures investigated by Henry Jenkins (2006, 2008), in which the fans actively embrace and expand the stories they at the same time consume.

Also, in the video game *That Dragon, Cancer*, the player is invited to interact and participate in doing cancer but in a different way. Although the gameplay allows the player to assume the role of caregiver, the interactive and participatory dimension is limited by the game, which lets him or her move through a number of preplanned narrative steps. As a player, one cannot influence the narrative in any direct way. Yet, it is hard as a player not to engage emotionally, which is emphasized by the opportunities for the player to linger in various situations, caring for the deathly ill Joel.

Finally, in comparison with *La Cura* and *That Dragon, Cancer*, the blog *In My Body* distinguishes itself by the way Gidlund acknowledges but explicitly declines the interactive and participatory dimension often viewed as one of the most prominent medium-specific features of the blog format. Even though, it was ini-

tially intended for passive reading the blog soon created an engaged audience of commenters. Together, its readers opened up and transformed the blog into a platform for collectively sharing experiences of cancer. This illustrates that doing cancer in digital media is not only up to the blog author, video game maker, or curator, but is also up to the audience and its motivation to interact and participate.

References

- Aaslestad, P. (2009). *The Patient as Text. The Role of the Narrator in Psychiatric Notes, 1890-1990.* (Erik Skuggevik & Deborah Dawkin, Trans.). Oxford & New York: Radcliffe Publishing.
- Andersson, Y. (2017). Blogs and the Art of Dying. Blogging With, and About, Severe Cancer in Late Modern Swedish Society. *OMEGA - Journal of Death and Dying, Online First*, July 2017, 1-20. <https://doi.org/10.1177/0030222817719806>
- Arduser, L. (2017). Remediating Diagnosis. A Familiar Narrative Form or Emerging Digital Genre. In Carolyn R. Miller & Ashley R. Kelly (Eds.), *Emerging Genres in New Media Environments* (pp. 63-78). Cham: Palgrave Macmillan. https://doi.org/10.1007/978-3-319-40295-6_3
- Bolaki, S. (2016). *Illness as Many Narratives. Arts, Medicine and Culture.* Edinburgh: Edinburgh University Press. <https://doi.org/10.3366/edinburgh/9781474402422.001.0001>
- Bolter, J. D. & Grusin, R. (1999). *Remediation. Understanding New Media.* Cambridge, Massachusetts: MIT Press.
- Breuer, J. & Bente, G. (2010). Why So Serious? On the Relation of Serious Games and Learning. *Journal for Computer Game Culture*, 4(1), 7-24. <http://www.eludamos.org/index.php/eludamos/article/view/vol4no1-2/150> (accessed 2.9.2018)
- Brough, M. (2014). Participatory Culture. In Marie-Laure Ryan et al. (Eds.), *The Johns Hopkins Guide to Digital Media* (pp. 382-387). Baltimore: Johns Hopkins University Press.
- Bruns, A. (2008). *Blogs, Wikipedia, Second Life, and Beyond. From Production to Produsage.* New York: Peter Lang.
- Bury, M. (1982). Chronic Illness as Biographical Disruption. *Sociology of Health & Illness*, 4(2), 167-182. <https://doi.org/10.1111/1467-9566.ep11339939>
- Conway, K. (2007). *Beyond Words. Illness and the Limits of Expression.* Albuquerque: New Mexico Press.
- Couser, G. T. (1997). *Recovering Bodies. Illness, Disability, and Life Writing.* Madison, Wisconsin: The University of Wisconsin Press.
- Couser, G. T. (2009). *Signifying Bodies. Disability in Contemporary Life Writing.* Ann Arbor: University of Michigan Press. <https://doi.org/10.3998/mpub.915367>
- Couser, G. T. (2017). *The Future of Life Writing: Body Stories.* a/b Auto/Biographical Studies, 32(4), 379-381. <https://doi.org/10.1080/08989575.2017.1289016>
- Delfanti, A. & Iaconesi, S. (2016). Open Source Cancer: Brain Scans and the Rituality of Biodigital Data Sharing. In Darin Barney, et al. (Eds.), *The Participatory Condition in the Digital Age* (pp. 123-143). Minneapolis: University of Minnesota Press.

- Diedrich, L. (2007). *Treatments. Language, Politics and the Culture of Illness*. Minneapolis: University of Minnesota Press.
- Ensslin, A. (2014). *Literary Gaming*. Cambridge: The MIT Press. <https://doi.org/10.7551/mitpress/9450.001.0001>
- Frank, A. (1995). *The Wounded Storyteller. Body, Illness, and Ethics*. Chicago: University of Chicago Press. <https://doi.org/10.7208/chicago/9780226260037.001.0001>
- Garde-Hansen, J. & Gorton, K. (2013). *Emotion Online. Theorizing Affect on the Internet*. Basingstoke, Hampshire: Palgrave Macmillan. <https://doi.org/10.1057/9781137312877>
- Genette, G. (1997). *Paratexts. Thresholds of Interpretation*. Cambridge: Cambridge University Press.
- Gidlund, K. (2011). *Det finns något som jag måste berätta. I kroppen min*. <https://ikroppenmin.blogspot.com/2011/03/det-finns-nagot-som-jag-maste-beratta.html> (accessed 21.8.2018)
- Gidlund, K. (2013a). *Gam. I kroppen min*. <http://ikroppenmin.blogspot.com/2013/04/gam.html> (accessed 21.8.2018)
- Gidlund, K. (2013b). *I kroppen min. Resan mot livets slut och alltings början*. Stockholm: Forum.
- Gidlund, K. (2013c). *I kroppen min. Vägsjäl*. Stockholm: Forum.
- Gubar, S. (2016). *Reading & Writing Cancer. How Words Heal*. New York: W. W. Norton & Company.
- Hale, B. J., Gonzales, A. L. & Richardson, M. (2018). Vlogging Cancer. Predictors of Social Support in YouTube Cancer Vlogs. *Cyberpsychology, Behavior, and Social Networking*, 21(9), 575-581. <https://doi.org/10.1089/cyber.2018.0176>
- Hawkins, A. H. (1999). *Reconstructing Illness. Studies in Pathography*, 2. ed. West Lafayette, Indiana: Purdue University Press.
- Iaconesi, S. (2012a). *La Cura - The Cure*. <https://web.archive.org/web/20130719054951/http://opensourcecureforcancer.com:80/> (accessed 27.3.2019)
- Iaconesi, S. (2012b). *My Open Source Cure*. YouTube 10.9.2012. <https://youtu.be/5ESWiBYdiN0> (accessed 3.9.2018)
- Jenkins, H. (2006). *Fans, Bloggers, and Gamers. Exploring Participatory Culture*. New York: New York University Press.
- Jenkins, H. (2008). *Convergence Culture. Where Old and New Media Collide*. New York: New York University Press.
- Jurecic, A. (2012). *Illness as Narrative*. Pittsburgh: University of Pittsburgh Press. <https://doi.org/10.2307/j.ctt5hjr8p>
- Kennedy, J. (2016). In the Blood. Mapping Narrative Circulation in Online Leukemia Networks. In Helen Thomas (Ed.), *Malady and Mortality. Illness, Disease and Death in Literary and Visual Culture* (pp. 59-72). Newcastle upon Tyne, UK: Cambridge Scholars Publishing.
- Lichty, P. (2012). *La Cura: An Open Source Cure. An Interview with Salvatore Iaconesi. Furtherfield*. <https://www.furtherfield.org/la-cura-an-open-source-cure-an-interview-with-salvatore-iaconesi/> (accessed 21.8.2018)
- Lind, R. A. (Ed.) (2012). *Producing Theory in a Digital World. The Intersection of Audiences and Production in Contemporary Theory*. New York: Peter Lang.
- Lind, R. A. (Ed.) (2015). *Producing Theory in a Digital World 2.0. The Intersection of Audiences and Production in Contemporary Theory*. New York: Peter Lang. <https://doi.org/10.3726/978-1-4539-1629-2>
- Lindroth, M. (2013). *Klarsynt gåva från dödens väntrum*. Göteborgs-Posten 10.5.2013.

- McNeill, L. (2003). Teaching An Old Genre New Tricks. *The Diary on the Internet. Biography*, 26(1), 24-47. <https://doi.org/10.1353/bio.2003.0028>
- Nesby, L. & Salomonsen, A. (2016). Youth Blogging and Serious Illness. *Medical Humanities*, 42(1), 46-51. <https://doi.org/10.1136/medhum-2015-010723>
- Osit, D. & Zouhali-Worrall, M. (2015). *Thank You for Playing*. <http://www.thankyouforplayingfilm.com> (accessed 11.3.2019)
- Page, R. E. (2012). *Stories and Social Media. Identities and Interaction*. London: Routledge <https://doi.org/10.4324/9780203148617>
- PewDiePie. (2016). *This Game Will Make You Weep (That Dragon, Cancer)*. YouTube 29.3.2016. <https://www.youtube.com/watch?v=xBQYLXX2Mk0> (accessed 11.3.2019)
- Quinn, Z. (2013). *Depression Quest*. <http://www.depressionquest.com/#info-section> (accessed 1.9.2018)
- Rettberg, J. W. (2014). *Blogging*. Cambridge: Cambridge University Press.
- Schmidt, W. (2013). Implied reader. In Peter Hühn et al. (Eds.), *The Living Handbook of Narratology*. Hamburg: Hamburg University Press. [hup.sub.uni-hamburg.de/lhn/index.php?title=Implied Reader&oldid=2015](http://www.hup.sub.uni-hamburg.de/lhn/index.php?title=Implied+Reader&oldid=2015) [accessed 1.3.2019]
- Schrier, K. (2016). *Knowledge Games. How Playing Games Can Solve Problems, Create Insight, and Make Change*. Baltimore: John Hopkins University Press.
- Schott, G. (2017). That Dragon, Cancer. Contemplating Life and Death in a Medium that has Frequently Trivialized Both. *DiGRA '17. Proceedings of the 2017 DiGRA International Conference*, 14, 1-10. <http://www.digra.org/digital-library/publications/that-dragon-cancer-contemplating-life-and-death-in-a-medium-that-has-frequently-trivialized-both/> (accessed 21.8.2018)
- Sontag, S. (1978). *Illness as Metaphor*. New York: Farrar, Straus & Giroux, cop.
- Sorapure, M. (2003). Screening Moments, Scrolling Lives. *Biography* 26(1), 1-23. <https://doi.org/10.1353/bio.2003.0034>
- Stage, C. (2017). *Networked Cancer. Affect, Narrative and Measurement*. Cham: Palgrave Macmillan. <https://doi.org/10.1007/978-3-319-51418-5>
- Tembeck, T. (2017). Autopathographies in New Media Environments at the Turn of the 21st Century. In Carolyn R. Miller & Ashley R. Kelly (Eds.), *Emerging Genres in New Media Environments* (pp. 207-223). Cham: Palgrave Macmillan. https://doi.org/10.1007/978-3-319-40295-6_11
- That Dragon, Cancer. (2016). *Numinous Games*. <http://www.thatdragoncancer.com/#home> (accessed 11.3.2019)
- Williams, S. (2000). Chronic Illness as Biographical Disruption or Biographical Disruption as Chronic Illness? Reflections on a Core Concept. *Sociology of Health & Illness*, 22(1), 40-67. <https://doi.org/10.1111/1467-9566.00191>
- Wikipedia. *HopeLab*. <https://en.wikipedia.org/wiki/HopeLab> (accessed 3.9.2018)