health:

Proud2Bme: Exploratory research on care and control in young women's online eating disorder narratives

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Abstract

Illness narratives have been studied to understand the patient's point of view. These narratives are becoming more prolific, accessible, and specialized, thanks to the improved Internet access and the growth of health-specific online communities. This article analyses illness narratives posted on a Dutch eating disorder website hosted by a treatment centre. Specifically, we look at 'care of the self' and 'control'. The young women wrote about controlling situations with disordered eating as a self-care tool, about being controlled by the disorder and about regaining control over the disorder. The website, with the opportunity for constant, unseen supervision, coercion through comments, and steering through edits and comments, revealed various modalities of control. While issues of control and eating disorders have been explored by others, little work has been done on how the control experienced by the young women (coercion on the individual, the body as the object of control, and the modality of pressure and supervision) interact, how control is presented in stories for a recovery-

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focused, monitored website, and how the website directs the content. As recovery-focused, therapist-led website is likely to continue growing, understanding how and why young women talk about care and control in the context of such websites is an important topic.

Keywords
experiencing illness and narratives, gender and health, research methodology, technology in health care

Introduction

> I especially want to make it clear in my story that I have muddled along with all my problems for many years. That's why I am so pleased with Proud. If I had had such a website when I was a teenager, it all might have turned out differently. No one had heard of BED [Binge Eating Disorder], even dieticians and doctors knew nothing about it, and here [on the site] you can get lots of information from professionals. You can get so much support from the users and from the experienced experts; it takes you out of that damned isolation. (Story 12)

Why do people tell stories about their lives, including the stories of their illnesses? Where and why do people tell these stories? What does it mean when the stories are written and posted online on a recovery website, rather than spoken to a therapist or researcher? What do the stories tell us, beyond the stories themselves?

This article explores these questions through the study of an online eating disorder support community hosted by a treatment centre. Specifically, we analyse the discourse that the authors used when writing stories of their eating disorders, especially with regard to how different manifestations of control and discipline impact their lives, eating disorders and participation in their online community. We also look at how the stories themselves are steered and disciplined by the structure of the site, site participants and staff from the hosting eating disorder treatment centre. For the purpose of this article, we analyse the stories using Foucault's definition of discipline, which is composed of multiple modalities of control: 'subtle coercion' on the individual, the body as the object of control, and 'uninterrupted, constant' pressure and supervision (Foucault, 1995). We analyse the different forms control take in and through the stories, especially but not solely focusing on the role of control in eating disorder illness narratives.

Background

In the Netherlands, as a recent review of research has shown, rates of anorexia nervosa have increased to 7.7 per 100,000 in 1999 from 7.5 in 1985; young women (15–19 years old) make up 40 per cent of all cases of anorexia, with young men representing less than 1 per 100,000 (Smink et al., 2012). Rates of bulimia nervosa dropped in the same period, from 8.6 per 100,000 in 1985–1989 to 6.1 in 1995–1999; however, the data also revealed that the age of onset (or diagnosis) of bulimia nervosa has been dropping as well, with diagnosis occurring at ages 15–25 years rather than, as was previously, 25–29 years (Smink

et al., 2012). Less information about rates of Eating Disorders Not Otherwise Specified (EDNOS) and Binge Eating Disorder (BED) is available for the Netherlands; in the case of BED, an article by Preti et al. (2009) revealed a lifetime prevalence of 1.9 per cent of women in six European countries, including the Netherlands. Despite the relatively high prevalence, few Dutch young women with an eating disorder ultimately receive mental health treatment (Van Son et al., 2010). Many young women delay treatment for their eating disorder due to shame, waiting lists or poor treatment centre match (De la Rie et al., 2006; Escobar-Koch et al., 2010; Hayaki et al., 2002). Early identification and treatment for eating disorders are highly desired by the eating disorder treatment community. Alternative methods of reaching and treating young (wo)men with eating-disordered behaviour, such as recovery websites, are a means of reaching this population.

Eating disorder treatment centres, recovery advocates and young women supporting eating-disordered behaviour have been developing websites for those with an eating disorder. Pro-anorexia and pro-bulimia websites have been developed and visited by (primarily) young women who want to continue or are continuing in their disordered eating (see Norris et al., 2006, among others); recovery/support websites include those hosted by eating disorder treatment centres (as was studied for this article). As Rich (2006) found in her study of anorexic patient narratives, young women with eating disorders often feel most understood when interacting with others with an eating disorder, whether online or in-person. This interaction comes in the form of participating on message boards, reading postings, writing poetry, sharing photographs and/or storytelling, such as sharing their experiences with illness, treatment and/or recovery using a traditional story arc (having a beginning, middle and end; chronological; intended for an audience) (Greenhalgh and Hurwitz, 1999).

(Online) illness narratives

Storytelling is communication of lives and experiences and of impressions and interpretations. The importance of narratives, as Hyden (1997) illustrated, 'lies in its being one of the main forms through which we perceive, experience, and judge our actions and the course and value of our lives' (p. 49). When people tell the stories of their illnesses, especially of chronic or long-term illnesses, they are using it as a means to understand, explain and interpret their illnesses in relation to their life and life history (Williams, 1984). These stories are a potentially fertile source of research data; when reading and interpreting unsolicited illness narratives, researchers, clinicians and policy-makers have the opportunity to understand the patient experience when it is not directed towards a clinician, possibly revealing a more unfettered story of illness, treatment and/or recovery (O'Brien and Clark, 2012). As Greenhalgh and Hurwitz (1999) noted, illness narratives invite interpretation by the readers, whether those readers are others with a similar illness, clinicians or researchers. In research, illness narratives can help to focus on patients' needs, confront prior knowledge and help form new theories and hypotheses about care, treatment and patient experiences (Greenhalgh and Hurwitz, 1999). Yet, benefits of illness narratives to research are not limited to these points. As will be shown in our research, analysing and interpreting online and unsolicited narratives can also substantiate research conducted in other ways (such as interviews, surveys, and observations); allow researchers to gain information about vulnerable, hard-to-reach and/or hidden

populations with little impairment to that population; and conduct research in and on new locations of health care (websites, YouTube and Twitter).

Formal illness narratives have been traditionally part of medical history taking as an attempt to understand patient experiences with illness, especially chronic illnesses (Bury, 2001; Greenhalgh and Hurwitz, 1999). Websites and forums provide fresh spaces for individuals to gather social support through the telling of their experiences, as seen in research on online eating disorder forums (McCormack, 2010) or in social networks (Juarascio et al., 2010), as well as in research done on online weight loss support groups (Hwang et al., 2010), HIV/AIDS online communities (Mo and Coulson, 2008) and infertility sites (Malik and Coulson, 2008). In the eating disorder literature, it is clear that writing is a form of personal interpretation and analysis of the causes and recovery from eating disorders, whether guided by therapists (Schmidt et al., 2002), for oneself (Hay and Cho, 2013) or for a community of peers online (Darcy et al., 2010; Dias, 2003; Riley et al., 2009). (Online) writing allows for the creation/manipulation of the self and personal histories in a public forum, as seen in work done on online gender presentation (Van Doorn et al., 2007), for personal empowerment (Pitts, 2004), for accountability (Leggatt-Cook and Chamberlain, 2012) and for self-disclosure.

Internet-based resources provide flexibility for people to learn how to tell the story of their illnesses and to seek support through reading others' stories; researchers suggest that this online storytelling has implications for how people understand health (care) and implications for the new politics of disease and of the body that emerges in online communities of practice (Akrich, 2010; Ziebland and Wyke, 2012). By posting stories online, the users form part of online communities, gaining and offering support, setting community norms, educating others, forming and shaping identities, and sharing experience. For many members of online communities, the distinction between online and offline worlds is blurred, with online activities affecting offline ones. Online stories offer the possibility to understand online communities, site dynamics and norms, and issues behind the illness narratives, including those of control.

Control and eating disorders

While the term 'eating disorders' encompasses a variety of physical and mental health problems (such as BED or excessive exercise), two of the more commonly researched eating disorders are anorexia nervosa and bulimia nervosa. Control is expressed differently in the minds and bodies of those with bulimia or anorexia. As research on young women with anorexia shows, the women saw themselves as attempting to control and process their lives by reducing food intake (Skårderud, 2007). Other work with young women with anorexia revealed that bodies were seen as the only thing that women could control by not eating, but noted that these behaviours quickly spun out of the women's control to the point where the anorexia became an identity (Malson, 2004). The disordered thinking was embodied, manifest in the young women's physical forms. Young women with anorexia were aware that they were controlling their bodies due to personal unhappiness, yet took pride and found joy in the control that they exerted; control over the body and emotions was found to be more important than changes in appearance (Dignon et al., 2006; Malson, 2004). Young women with bulimia reported feeling out of

control of their eating and sought to regain control through purging (Fairburn and Harrison, 2003), as well as literally and figuratively ridding themselves of bad feelings by vomiting or using laxatives (Polivy and Herman, 2002). For those with anorexia, bulimia, BED or EDNOS, what the young women were feeling and thinking impacted their bodies (and vice versa).

Sex and gender play strong roles in eating disorders and issues of control. While growing numbers of young men are developing eating disorders, eating disorders are thought to predominantly impact young women in the Netherlands at this time (Smink et al., 2012). It is important to keep in mind that female bodies are disciplined differently than male bodies; eating disorders reflect this social and personal disciplining of the female body. As King (2004) noted, the 'female body exemplifies Foucault's arguments about discipline', in that the female body is frequently disciplined into socially acceptable forms in ways specific to women (p. 30). This disciplining has happened over time, Bordo (1997) wrote, as women's bodies have been historically subject to more cultural manipulation of bodies than those of men, whether through physical manipulation of the body through eating disorders or through the limiting of education and career opportunities.

The language of control is pervasive in discussions of eating disorders; this discourse is found in research on eating disorder treatment, on pro-anorexia sites, and on the experiences of young women with eating disorders (Bell, 2009; Bemporad, 1996; Claes et al., 2012; Gremillion, 2003; Malson et al., 2008, 2011; Riley et al., 2009; Roth and Armstrong, 1990). This discourse is also present in eating disorder narratives in culture and media as well, including in the Netherlands; journalist Maartje Laterveer wrote, in the June 2014 issue of *Dutch Vogue*, 'I thought that I had everything under control. But I had long relinquished control to an eating disorder that I did know about, if I was honest' (p. 154). While control, eating disorders and young women have long been associated, there are gaps in this understanding. Less is known about what types and how the different modalities of control act and interact in young women's written, unsolicited illness narratives.

In this article, we used a novel method of data collection to gather and analyse how users of an eating disorder support website wrote about control in the stories of their eating disorders and what the impacts of control were on the authors, their illness narratives and the treatment providers. As the illness narratives analysed here were posted on a monitored eating disorder recovery website, the research presented in this article is an opportunity for readers to understand how the online community, recovery support website, and illness narratives (inter)act in regard to the modalities of control, as well as to understand how the data collected online fit with the larger literature on eating disorders and control. As less was known about how online communities form a new arena for discussing, exerting, and tinkering with issues of control, this research shed light into the growing world of monitored online illness communities. In addition, this article illustrated a deeper understanding of how the types of control interact and serve, ultimately, to discipline the lives of authors, the stories that they tell and the website that they participate in.

Theoretical underpinnings

The theoretical underpinnings of this article stem primarily from the work of Foucault on the technologies of power and, secondarily, on his work on the technologies of the self. As Foucault (1988) noted,

technologies of power … determine the conduct of individuals and submit them to certain ends or domination, an objectivizing of the subject, [while] technologies of the self … permit individuals to effect by their own means or with the help of others a certain number of operations on their own bodies and souls, thoughts, conduct, and way of being, so as to transform themselves in order to attain a certain state of happiness, purity, wisdom, perfection, or immortality. (p. 18)

For a better understanding of technologies of power, we refer to Foucault's (1995) work on the penal system; *Discipline and Punish* explored how bodies and minds are shaped to internalize discipline by external actors, including the people in and the architecture of schools, prisons, hospitals and churches. This shaping comes via initially external forms of discipline, which are exercised through different modalities of control: discrete coercion and steering through, for example, creation of daily routines, the creation and discovery of the body as a subject of power such as through medical and prison structures and (seemingly/potentially omnipresent) surveillance through panoptic physical structures (Foucault, 1995). As seen in the literature on online narratives and in the literature on eating disorders, one of the more remarkable ways in which the technologies of power can be seen is through surveillance (Conrad, 2009; Dryburgh and Fortin, 2010; Leistert, 2012; Rich and Miah, 2009; Walstrom, 2000). This surveillance stems from multiple origins: the change towards new forms and implementations of surveillance within health care, especially in non-acute illnesses (Armstrong, 1995); the use of surveillance in eating disorder treatment in specific (Gremillion, 2003); the self-surveillance inherent in having an eating disorder (Bell, 2006); and the surveillance and governance of online activities, including those related to health care (Eysenbach, 2011; Walstrom, 2000). Gender plays a key role in the surveillance and control of bodies, thoughts, and activities. As feminist scholars have pointed out, women's bodies are watched (and, resultantly, controlled) in different ways than are those of men – by their families, society at large, the medical profession, and themselves (Bordo, 1997; Conrad, 2009; Corones and Hardy, 2009; Gestaldo, 1997).

The watching of one's self is a form of self-care and an aspect of technologies of the self. Technologies of the self, understood simply, is working on one's self, often for self-improvement and taking care of one's self; without observing and knowing oneself, it is difficult, if not impossible, to care for the self. Here, writing plays a key role. As noted by Foucault (1988),

Writing was also important in the culture of taking care of oneself. One of the main features of taking care involved taking notes on oneself to be reread, writing treatises and letters to friends to help them, and keeping notebooks in order to reactivate for oneself the truths one needed. (p. 27)

Writing and re-reading illness narratives provide one with the opportunity to take care of the self, to self-improve and to communicate those lessons learned about self-improvement to others. This writing is not, as Foucault (1988) showed in *The History of Sexuality*, necessarily done in isolation but is conducted as part of a self-improvement culture. The self, in many ways, is developed through care, whether through writing, self-care activities, or interacting with others. The technologies of power and the technologies of the self are interwoven in the lives and stories of the authors. While writing allows for the further care

and development of the self for oneself and for/in one's community, this writing is not just a technology of the self but is a technology of power as well. As our research will show in the following sections, the self is cared for and created through the online writings and postings of the young women.

Methods

The stories reviewed in this research were posted on a Dutch eating disorder support website called Proud2Bme. The Clinical Director at the Ursula Centre for Eating Disorders, other professionals at the Ursula Centre for Eating Disorders and patients helped to develop Proud2Bme in 2008 to fill a gap in educational and supportive services, including providing an alternative to pro-anorexia sites, for the growing number of young women with eating problems.

As a currently active online support and education centre, Proud2Bme promotes positive self-image, healthy eating and treatment for eating disorders through participation in forums, chats with dieticians and psychologists, news on eating disorders, inspirational messages, beauty and fashion pages, blogs written by site participants, and stories about living with eating disorders. While the website states that it is a resource for everyone, most of the postings focus on information of interest to women in high school and at university, such as healthy eating and team sports, eating disorders and school stress, and advice on how to tell parents, teachers and friends about an eating disorder. The site's look and feel is also directed towards young women, featuring photographs and vector images of younger looking women on a pink background. These cues, as well as a statement on the webmaster's 'About' page, have led us to believe that the site was (and is) targeted towards youths and young adults. Some of the articles are directly written to family members of those with an eating disorder or are tagged with the tag 'parents'. While the site contains information about eating disorders with formal diagnosis criteria, such as anorexia nervosa, bulimia nervosa, and BED, much information is also provided about sub-clinical eating disorders or problems, atypical disorders such as excessive exercise or orthorexia, and other issues with food, body image and mental health, such as cutting or depression. According to the site's 'About' page, over 200,000 unique visitors access the website each month; over 20 volunteers work on the website, as well as 2 website editors who have experience in eating disorders, 2 other part-time employees, and various psychologists and dieticians from the centre. The website has been advertised in the media; has active YouTube, Instagram, Pinterest and Twitter accounts; has an app; and is linked off of multiple mental health and lifestyle websites. The website has spawned a US version as well.

The stories were divided into four categories on the site: experience stories, interviews, famous and special people, and the psychology of … (www.proud2bme.nl).[1] As the site was and is primarily targeted to young women and their families, we have assumed that the majority of the stories analysed were written by young women (which we define as high school and university-aged). The 'experience stories' were and are stories written by young women about their life with an eating disorder, including the development of the disorder, revealing the eating disorder to adults in their lives, treatment paths, relapse and current circumstances. Some, but not all, of the analysed stories

contained photographs of the authors, supporting the assumption that the majority of the authors were young women; one story out of the reviewed stories had a photograph of a young man as the author, while the remaining had photographs of young women, of nature scenes, or of inspirational messages. While some aspects of the site require the user to create and use a log-in, much of the site, including the stories analysed in this article, was and is open to the public.

   These data were gathered as part of a larger study. The Ethics Board of the Erasmus University approved the data collection of an overarching study. For this article, we specifically focused on the Proud2Bme website. We took various steps to ensure ethical data collection, following the example of other Internet health researchers (Murray and Sixsmith, 2002; Robinson, 2001). For this article, data were collected exclusively from the public pages of the website. As the stories were posted on the public pages of a frequently visited website, we assumed that the authors did not solely write for a private community (as might be inferred in some forums and sites that require a log-in) but were writing for an audience. As Hookway (2008) noted about blogs, 'blogging is a public act of writing for an implicit audience'. In addition, the centre's director approved data collection on the Proud2Bme website. The quotes from the stories, which were frequently anonymous when posted on the site, have been further anonymized, with no reference to the title of the story or locations. Translation from Dutch to English provided a further level of anonymization. While issues might arise from translation, as the focus is on narrative, efforts were taken to reduce these issues; translation was done by the first author (B.H.W.) (a native English speaker) and verified by a native Dutch speaker. Translation also allowed for the checking of quote relevancy and coding.

Procedure

We reviewed all 'experience stories' and the comments that were written between 4 November 2009 (the first story posted on the site) and 11 July 2011 and collected data from the stories, which were coded into themes. However, the comments were not analysed for this article, as we were mainly interested in the presentations of the young women on this site at this time, rather than in the interactions on the site; as well, we were concerned about the anonymity of the comments. As the comments were tied to user names, which were used for any comments that the website users posted, the comments were less anonymous than the stories and not included in the analysis.

   To be included in the study, the stories had to be written for and posted on the public section of the site as 'experience stories'; while the website had much more content and grows continuously through the postings of website staff and users, we limited the data collection to these stories, as the stories were on the public part of the website, were written by users of the website and were (in principle) written as complete narratives. This resulted in the collection of 94 'experience stories'. One of the 94 stories collected focused on self-harm, rather than life with an eating disorder; this story was not included in the analysis for this article. One of the included stories was written by a young man; based on pronouns, names, gendered words (such as daughter, school girl), photographs of the authors and the fact that eating disorders were and are more common among young women, we assumed that the remaining authors were young women.

While it was not fully possible to know exactly who each of the authors were (e.g. in terms of class, age and background) and knowing that this can present challenges in terms of how we were to read the data, the data were taken at face value. Taking the data at face value allowed us, as researchers, to read what other users of the site were able to read, including those who do not have a log-in. This was a useful attribute to our research; we researched what the authors wanted to share with the public through writing and posting their stories. However, this can also be a limitation. As the stories were posted anonymously, it was not possible to contact the authors for additional information or clarification; just as the users of the website were, we were left with the information that the stories revealed, educated estimates of demographics rather than precise data on education, age, location and unanswered questions. As we analysed the stories as they were posted online (rather than stories of the young women told to us directly), further information and clarification were not needed for our analysis. Since the young women wrote in Dutch on a Dutch website, we were able to make a few important assumptions: that the young women had access to health insurance, as coverage is mandatory in the Netherlands and in Belgium (two locations where Dutch is commonly spoken); that the young women were writing for a Dutch-speaking audience of primarily young women; and that the young women were writing for an audience that was interested in eating disorders and eating problems, as the site where the stories were posted promotes support for those with an eating disorder or eating problems.

By collecting data from a public support site for those with an eating disorder, we were exploring control by using a fairly novel methodology: online-only data collection from illness narratives. This exploration allowed us to understand how young women posted about control, what they considered important aspects of their stories and how the young women wrote for a monitored community; it also allowed us to be unobtrusive (yet ethical!) researchers on a very sensitive physical and mental health issue.

Data analysis

The remaining 93 experience stories were analysed deductively as well as inductively; upon reading the stories, we realized how 'control' was one of the main themes in the stories and, as a result, decided to focus on this theme more in detail using thematic analysis. All stories were first read closely to establish general knowledge of the data. Each story was then reread and coded into themes by B.H.W., based on the discourse and content of the stories. A memo sheet was made in Word by B.H.W. for each theme, and references to original material representing that theme were recorded under each theme. The major themes uncovered in the stories were present in the majority of the narratives in various ways; however, how these themes were presented by the authors and analysed by the authors varied based on the context of the stories. The data were iteratively analysed and reflected upon by B.H.W. and the co-authors throughout the coding, translation, and writing processes.

Findings

Eating disorders and control

The young women used a variety of discourses when writing about control and their eating disorders or problems, including disordered eating behaviour as a tool to control a

disordered life, eating disorders that took control of life, treatment for eating disorders and control, and regaining control while recovering from an eating disorder. This was a major theme in many of the illness narratives and was often quite explicit in the narratives. The eating disorder was sometimes described as a tool, as the young women wrote of using disordered eating behaviour to govern their lives, circumstances, and/or emotions; these tools were a technology of the self, even if the self-care was often registered as self-harm by others:

> The only thing I could do outside of my mom's control was eating. I longed to have something of my own so much and it's just sad that apparently eating was my only way out. (Story 1)

> I took up weight loss again, skipped meals, threw up and took laxatives. I was searching for control, control that I couldn't find in my life, but I found it in weight loss. (Story 2)

The young women wrote of using eating behaviours as methods of self-care and independence from the direction and manipulation of others; they were governed by 'the control, guidance, sway and mastery of others' (Rose, 1999: 16). Control was highly sought after, whether control of eating or of body weight, as the second quote reveals. This control can be understood as the ways in which their bodies were the objects of control, as enacted by themselves to manage difficult situations. Eating/not eating/purging was their 'own' and was the control that was unavailable in other arenas of their lives.

However, this was a battle. Parents were often described as controlling the young women and pushing young women into less eating-disordered behaviours. As a result, the young women's bodies and behaviours 'became the issue of a conflict between parents and children' (Foucault, 1980: 57). The young women wrote of seeing their behaviour as tools for controlling difficult circumstances and emotions, while family, friends, or clinicians were reported to have seen the behaviour as an illness in need of medical attention, thus creating a conflict over bodily control. This conflict, in some cases, continued throughout treatment, as the young women wrote of resisting the efforts of parents, teachers and friends to take part in treatment.

Writing, eating disorders and control

The young women's stories followed a common narrative trajectory, starting with disordered eating *behaviour* as a tool for controlling an unruly life, followed by awareness of the behaviour as an eating *disorder* and an exploration of how the eating disorder took control:

> Weeks go by and it's getting worse, until I go to the doctor in a panic. I couldn't take it anymore. I wanted to be myself again and it wasn't working. The control over my own life was dominated by something inside me and at that moment, I came back. The control that I thought I had appeared to be no control at all. (Story 3)

What had been a set of tools to manage difficult situations was reclassified by the young women on a public forum as a disorder; at times, this reclassification was seen as coming from parents, rather than from the young women themselves. The authors of the narratives

frequently used discourses of subjugation when writing of the disorder. The disorder 'dominated' them, despite their efforts and without their full knowledge. As seen in the quote above, the disorder steered the young woman; the author wrote of 'not being herself'. This narrative and others revealed that eating-disordered behaviour was deeply internalized, yet remained external to identities.

The narratives described the various paths the young women took towards recovering from their eating disorder and recovering their identities, including via mental health treatment and support from friends, family and members of the online community. Sometimes, the writers noted that the path towards recovery was not chosen by the young women but was chosen for them:

> I had to go into mental health care. Every week, sometimes twice a week, I had to go there and every time I was weighed and measured. I thought it was awful. My mother also weighed me and I almost started to hate her for that. (Story 4)

The young women's stories revealed various sources of monitoring, often through observations of the metrics and behaviours associated with eating disorders; whether the young women chose therapy or were pressed into it, this theme was common throughout the narratives. As a result of this monitoring and observation, the young women interpreted their bodies as the objects of external, clinically driven control.

This external monitoring and regulation of their bodies through weighing and measuring was conducted by multiple actors, making the body the object of collective control. The young women's written narratives also documented how they were (not so subtly) coerced into less disordered behaviour and their frustration with this process of coercion. As was seen in the stories that the young women wrote for the recovery website, the bodies and minds of the young women were shaped by the various processes of control, even if the result was the young women 'almost hating' those who controlled and measured them. These modalities of control shaped young women's identities, which are 'the products of a relation of power exercised over bodies, multiplicities, movements, desires, forces' (Foucault, 1980: 74). This imparted a deeper understanding of how the young women framed control and their eating disorders, treatment and recovery for their online community.

The website and control

The website impacted the stories the young women wrote about their eating disorders; this theme was an undercurrent in all of the stories. In Foucauldian discourse, the possibility of being watched shapes behaviour; the guard does not need to be seen in the Panoptic tower to change how prisoners act (Foucault, 1995). The eating disorder recovery website, with its blinded watching, provided an excellent example of how observation and monitoring changed what the young women wrote. This potential for constant observation was a process of control on the stories that the young women wrote; it was built into the architecture of the website through monitoring by health care professionals, trained volunteers and other users of the site, and through Google Analytics, which collects metadata on the registered site users, pages visited and time on the site. The site's

data collection policy was stated on the site's privacy page, which was viewable without a log-in. In principle, the architectural nature of surveillance was made clear to the authors, but the users had no way of knowing if, when, or how their stories were read. The stories and comments themselves were monitored by one of the founders of the site, clinicians and/or site volunteers, with all mentions of weights, diet pill brands, and pro-anorexia websites replaced with 'xx':

> When I eventually lost weight again, they said that when I weighed xx, I had to be tube fed. (Story 15)

> At school, I didn't eat any more; I didn't find breakfast so necessary. So I actually ate 1 meal a day, took xx, and exercised a lot. (Story 16)

By replacing weights and diet pill brands with xx, the stories were edited, removing aspects that may have been significant to the young women. While the removal of taboo content was clearly demarcated with 'xx', it was not possible to know who removed the content. The content may have been removed by the site administrators, who monitored the discourse on the site to ensure body-positivity and to ensure the stories followed the site standards; the young women who wrote the stories may have removed the content themselves to meet the site norms and support the recovery of the other site users. However, this editing controlled the stories to the point of removing content that was relevant to more deeply understanding the young women's narratives.

The editing and steering of the stories was a continuous process. The stories did and do not end after the young women has posted them, but were/are continually changed through the comments sections, through adjustments in the location on the site and through edits by the webmaster. The information posted on the website created a record, available to be viewed at any time. As Nicoll (2008) noted in an exploration of e-learning environments, through this online record, the website users and their information were more open to observation, correction. and tracking. This correction came, in part, through the redaction of banned information, which also served as a public warning to others about the types of information deemed appropriate for the site.

Observation of online posting and activities by staff and users helped form the community, as young women wrote of finding the stories of others as a useful and supportive feature of the site. Through reading the words and looking at the photographs of others, the young women were able to present information directly to their community to thank other users, to present missing information or to support others. While this was implicit in many of the stories, some of the young women explicitly addressed their reasons for telling their stories in their illness narratives:

> The reason that I tell my story here? People often think that when you have an eating disorder, you are severely underweight. But you know, that is only a small part. Lots of people have struggled unnoticed and died. It has nothing to do with how you look on the outside – fat, thin, tall, short; anyone can struggle with it. I hope that people can come to see that you don't only have an eating problem when you can count your ribs, that it's about what is in your head. I hope that there is more understanding for people like me. (Story 9)

> The fact that there are so many girls and boys on Proud2Bme that fight to get better made me realise that I can also do it and more than that, I want to. I'm now stronger than before. I have control back, the real control. When I look in the mirror, I see myself as I am again. I have a handle on myself again. (Story 10)

The young women shared the lessons learned in their care of the self with the hope of training others to care for themselves and to inspire others. No matter the intention when posting the stories, the stories and identities expressed through the stories were (and still are, as the stories are still available online at the time of writing this article) being controlled, 'manipulated, shaped, trained' by the potential for comments, community norms, and surveillance by multiple actors at different times (Foucault, 1995: 136). Although the use of the word manipulation suggests a negative connotation, in this case it was seen by the authors as a positive force, protective and supportive. This control was welcomed by the young women; research on weight loss blogs revealed that comments from readers can serve as an important source of motivation and collaboration (Leggatt-Cook and Chamberlain, 2012). The young women posted their stories to be read, to be observed, and were (to a degree) aware of the potential for shaping that posted stories possessed.

While the rationale for posting their stories was implicit in many of the narratives, a few of the young women stated explicitly that their reasons for posting on the public forum of the site were to support others and to try to influence (and perhaps steer the direction of) external systems:

> With this petition, I hope that I can really achieve something, so that everyone who comes after me can get better treatment. I am grateful to Proud for giving me the chance to talk about the petition. (Story 11)

> I've had to come a long way to be able to write these words and share with you guys. I hope that with my story I can make the way to help and make recognition of the illness somewhat more traversable for those who have felt incomprehensible and alone because of cultural differences. (Story 14)

As research about an online community for the discussion of severe acute respiratory syndrome (SARS) shows, online writing can serve as a form of cultural and political resistance (Gillett, 2007). The online platform of the eating disorder website was an opportunity to point out and publicize the faults and gaps that they perceived in society and/or the current health-care system, whether it is faults seen in the lack of treatment options available, the impact of cultural issues on bodies, treatment and emotions, or in the treatment that they have personally received. Similar to what was seen in Akrich's (2010) work on online communities for pregnant women, the young women who were part of the community formed a type of activist group, collecting and sharing knowledge about the condition, mobilizing others and forming an epistemic community, producing new types of knowledge about their diseases and bodies. These young women were working, through their illness narratives, to steer the future of eating disorder support, treatment and recovery in their online and offline communities through attempts at coercion of those in power, as can be seen in the efforts to influence policy-makers through a petition.

Discussion

While eating disorders have long been associated with control, this work presents additional insights into the current research on control and eating disorders, as well as research on illness narratives; this research reveals the different manifestations of control apparent in young women's stories about their eating disorder, such as control manifested in and over the body, control and steering from outsiders like parents and treatment providers, control over the stories on the website by various actors, and control through oversight and supervision of the young women's bodies and stories. Through this work, we can see how young women wrote about control, about how these modalities of control impacted their lives, and how the stories were shaped by the website. While the illness narratives revealed many of the issues of control and eating disorders that were previously uncovered by researchers, this article adds to the literature by exploring the modalities of control, as well as by using data written by young women for other young women. Through this research, it is clear that the modalities of control were key features in eating-disordered behaviour, eating disorders, treatment, and recovery for young women, even when the young women were writing for themselves and for their recovery-oriented community. As online support communities are growing in number, this research can provide insight into how control and stories intertwine to create disciplined illness narrative authors.

Storytelling and control

Writing an illness narrative for an online community gives people the opportunity to explain their illness to themselves and to others (Hardey, 2002); in the case of the young women who wrote for the site, explaining their illnesses, offering support to members of these community and clarifying myths related to eating disorders were stated rationales for writing and posting the stories. The process of writing, however, may not have been simple. As was seen in the young women's stories, there was a crafting to written autobiographical stories, a pattern that was followed, a language that was used, an intentionality of what was revealed and what was kept back. The posted stories, like the young women who posted them, were weighed and measured. As Bell Hooks (1999) noted,

> Unlike therapy, where anything may be spoken in any manner, the very notion of the craft suggests that the writer must necessarily edit, shape, and play with words in a manner that is always subordinate to the desired intent and effect. (p. 14)

The act of writing an illness narrative allows, in general, for interpretation and re-interpretation, framing, targeting to an audience, reframing, and tinkering until a desired portrayal of the self and of their story is reached. This is especially true online, where the writing and rewriting self-narratives are common (Hardey, 2002). This is in contrast to posting on forums (such as on pro-ana sites), which often serve as quick message boards between users and do not often reveal complete narratives.

By telling their stories as participants of an online community, the writers were developing and strengthening relationships; as Frank (2000) wrote, storytelling forms, reforms

and elaborates the relationships between the storyteller and the audience. In the studied stories, this recursive relationship relied on writers, readers and the hosting institution to develop. The development of the relationship between the writers and the readers could be seen in the stories themselves, as the authors of the stories addressed their community directly for support, with gratitude or with further insight into the disorder. Much as Foucault (1988) stated, the young women were writing for themselves to care for themselves, as well as for their community; the stories posted online were the modern 'treatises and letters to friends to help them' (p. 27). The relationships formed through storytelling helped shape the online community with its own norms, expectations, surveillance structure, and language, including the language used when discussing the different modalities of control associated with disordered eating, an eating disorder, recovery, and posting stories online.

Control and eating disorders

The stories that the young women wrote for the eating disorder website were not linear tales of how the young women got sick and then got better, but were highly complex illustrations of lives (and the stories of these lives) in transition. Although control was often characterized as a singular entity by the young women, the stories revealed that control was not singular, nor enacted by one actor at only one point in time. Through what the stories said and where they were and still are posted, it is clear that different modalities of control, multiple actors and various forms of oversight impacted the authors' lives and stories. The narratives revealed that a complex network of relationships between writing, agents, actions and control was formed; this network was, as Foucault (1980) notes, a 'highly intricate mosaic' (p. 62). This mosaic included the actors such as the young women, the externalized eating disorder, their families, their treatment providers, the members of the online community, the actions of treatment and recovery, participating in the website, writing and posting their stories, and the ways in which control was acted out in and around the young women's lives and stories. The mosaic was not static but was a complex, moving network of actors and actions interacting in multiple ways over time in the stories and in the young women's lives.

The segments of the stories about treatment revealed the mosaic of actors, actions and the processes of control most explicitly. Treatment was described as involving the body as an object of control, coercion, and near-constant monitoring. Through treatment, the external, treatment-led modalities of control (such as weighing the young women, monitoring what they ate, and restricting access to the bathroom to limit purging) created discipline, which was exercised on the young women and their stories. In the young women's stories, this interplay of various modalities of control (coercion on the individual, the body as the object of control, and that of pressure and supervision) was conducted by different agents, with some actions revealing multiple modalities of control. For example, by insisting that the young women ate defined amounts of foods, the bodies were objects of control and the young women were pressured to learn how to eat and were supervised by nurses, parents and others until they ate. Sometimes, the young women wrote, there was a struggle against the supervision by others to eat and coercion of the eating disorder not to eat. As was seen in the

young women's narratives, treatment was an effort to discipline bodies and minds to improve the health of the young women.

Care for the self played an important role in the disciplining of the young women, as the narratives reveal. Eating-disordered behaviour was often begun in an attempt to care for the self, although the care of the self was seen as misguided by those around the young women and, often later, the young women themselves. However, as this technology of the self was understood to be more harmful than helpful, the young women were often forced to seek outside help in caring for themselves. Treatment and recovery-focused activities were some of the primary technologies of the self, as one of the goals of these activities was an internalization of the lessons learned from therapists, friends, family, clinicians, other users of the site, and others with an eating disorder. These lessons often focused on new ways to care for oneself, such as through healthier eating habits, connecting with others on the recovery-focused website and through maintaining a healthier weight (for those who struggled with extremely low weight). The young women wrote of being disciplined into care of the self by treatment, recovery-focused activities, and participating on the website.

In general, this discipline is not limited to eating disorders but can be seen in other programmes intent on the modification of women's bodies, as research by Cressida Heyes revealed. In her exploration of a commercial dieting programme, the article exposed the supervision of the body inherent in weight loss programmes, through the shifting of authority from the body to the mind and through the disciplining from both internal and external sources, such as weigh-ins and calorie logs (Heyes, 2006). This observation and coercion were also true for the treatment of eating disorders, as the stories from the young women revealed and as was shown in the literature (Bell, 2006; Gremillion, 2003; Malson, 2004; Warin, 2005). This literature, much like the young women's stories, revealed that treatment was situated within discourses of class, culture and gender, affecting young women's bodies, lives and, in turn, illness narratives in very specific, normalized ways. Much like research on diabetes has shown, the bodies and actions of the disorder, treatment and recovery were embodied (Mol and Law, 2004); eating/not eating, as shown in the example above, was how young women both did their bodies, disorders and stories and were their bodies, disorders and stories. Bodies and control were always present in the stories.

The notion of control that is pervasive in the literature on eating disorders was, through the analysis of the stories, more nuanced and clarified; through this analysis, it was possible to see that there are many versions of control (controlling what, by whom, and through what mechanisms) that compete, overlap, and influence the young women's lives and stories. The young women's illness narratives, intentionally or not, reflected the language of and the literature on the controlling and disciplining nature of eating disorder treatment. Whether this was due to the pervasive language of control surrounding eating disorders or a manifestation of the language of control of the online community was impossible to tell and, in all honesty, may not be that important; as Mol noted, attuning and adjusting is needed, as control is an illusion and the elements involved in lives, treatment and bodies are constantly moving (Mol, 2009). In this case, the attuning happened in the young women's lives and was reflected in their stories. What is important was that the young women wrote of how treatment disciplined them. The origin of the

notions of control in the stories is less important than the fact that it was important in the young women's lives and stories.

Insights for clinicians and those with eating disorders

For young women with an eating disorder, this research presents an opportunity to understand how the academic community understands the issues of control surrounding an eating disorder, storytelling about eating disorders and the impact of posting said stories on a recovery website. This analysis also provides those with an eating disorder the chance to see how others with an eating disorder present their stories and interact with others on a recovery site. The translation of the quotes allows for those who do not read Dutch to see how others in another culture experience an eating disorder. This article also shows that insights from the stories posted online are valuable not only to those with an eating disorder but also to a wider community, such as clinicians and researchers.

Clinicians and webmasters of recovery websites can benefit from this research by reading the narrative reproduction of the lived experience of those with an eating disorder, especially how those with an eating disorder experience control. As many young women with eating disorders were (and are) subject to treatment involuntarily, it can be useful to see how those with an eating disorder viewed the control exerted by treatment, whether this control was steering to make healthier choices, the physical control over the body by coercing eating or the control by family assisting in treatment. It is also useful for clinicians to see how those with an eating disorder recovered from the control of the eating disorder with the help from a virtual community, allowing the clinicians to see that there are other, less traditional resources available to help. Webmasters can see how such a website played a role in recovery and assisting those with an eating disorder in regaining control of their lives and how the monitored nature of the sites (indeed, the controlling of the stories) influenced the recovery-positive nature of the website. Through this research, webmasters and volunteers gain insight into the pathology of the disorder from the point of view of those with the disorder, as well as how the stories posted on the website fit into larger understandings of eating disorders and recovery.

Insights for researchers of individuals with eating disorders

This research and article provide insights for researchers of individuals with eating disorders by showing ways in which researchers can access the stories of those with an eating disorder: by looking at the illness narratives that those with an eating disorder post online on a recovery website. Collecting data from illness narratives provides researchers with the opportunity to review the complete story that the authors want to share. By analysing illness narratives posted online, the researchers have the opportunity to collect data about personal experiences with an eating disorder outside of a research setting. Through this method of collecting data, there is less research burden on a vulnerable population, as well as the ability to collect data in an asynchronous manner. However, ethical steps for online data collection should still be taken.

The analysis of control in the online eating disorder narratives also provides insights for researchers on aspects of control and discipline. While control is often treated as a

singular issue, our research reveals the benefits of nuancing the types of control, as well as understanding how these types of control interact and discipline. By taking a more nuanced understanding of control, researchers have the potential to explore under-researched or ignored aspects of control. This more nuanced look at control also benefits researchers through giving them the possibility of deeper insight into how discipline is created and enacted through different modes of control. Looking at control in this way may help researchers, for example, to analyse how disordered eating can be a form of self-care and how treatment (in a broad sense) can function to change the ways that different modes of control play in the lives of people with eating disorders.

Conclusion

Through this work, we laid a foundation for future endeavours concerning control, especially in regard to online illness narratives and eating disorders, as well as showed that the findings gathered through the novel data collection of analysis of online eating disorder illness narratives conform with the larger eating disorder and control literature.

   This research illustrated the technologies of power and of the self in how the young women and their stories were shaped by themselves, by the externalized eating disorder, by parents and treatment providers, by the structure of the website, by the website readers, and by members of the eating disorder treatment centre. This coercion was not uni-directional; as the stories revealed, some of the young women used their stories to raise recognition of cultural issues and eating disorders and to reduce gaps in knowledge surrounding less common eating disorders such as BED (as seen in the quote at the beginning of this article). The research also revealed the different ways young women wrote of their bodies as objects of control for an audience of their online peers. In addition, we can see that the structure of the website supervised and surveilled the stories through Google Analytics and through the constant availability of the stories; the young women who wrote them did not know when, if or by whom their stories were read. These modalities of control served to discipline the young women and their stories into acceptable forms.

   One of the important findings of this research is that the processes of control put forth by the website had a large impact on the young women's stories and lives. As online support communities are growing for those with eating disorder, understanding how the processes of control affect the lives and stories of those with an eating disorder has the potential to improve care both online and offline.

Limitations

This research has a few limitations. As the data were collected from anonymous stories on the public portion of a website, it was not possible to contact the authors for further information and clarification. The stories were posted by Dutch authors and were written in Dutch; however, the analysis revealed that the analysed data posted on the site were in line with data collected by other means (interviews, document analysis, and focus groups) and with data from young women from other countries, such as the United Kingdom (see, for example, Malson, 2004) and the United States (e.g. Gremillion, 2003).

Acknowledgements

Funding

Note

1. While the stories are still available on the website, the categorization has changed.

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