

Agencies and Experiences of the “Good Participant”: The Long-Term Trajectories of Patients Turned Media Participants

ESPEN YTREBERG
University of Oslo, Norway

KJERSTI THORBJØRNSRUD
Institute for Social Research, Norway

As a prominent case of media participants with a high moral status, medical patients have become central across media and platforms, particularly because journalists need them as exemplars. On the basis of in-depth interviews with 18 Norwegian patient-participants, this article investigates the agencies and experiences involved in longer spans of participation across mass and social media. The article shows that although communicating illness enables affirmative and meaningful forms of openness and sharing for patient-participants, over time stresses and conflicts also appear as participants negotiate the terms and limits of their self-disclosure in an effort to exercise agency over their illness stories. In general terms, the article argues for an approach to media participation that takes into account high-status forms of participation, multiple media, and participation trajectories over longer spans of time.

Keywords: media participation, long-term participation, patient-participant, personal audience, health journalism

The abundance of personal stories of illness in current media has revolutionized how health is discussed and understood in the public sphere. Whereas media coverage of health was traditionally seen as dominated by medical expertise (Hallin, Brandt, & Briggs, 2013), lay patients’ stories now play an increasingly prominent role in contemporary media representations (Coward, 2013; Hinnant, Len-Ríos, & Young, 2013; Stroobant, De Dobbelaer, & Raeymaeckers, 2018). The patient case or exemplar is a key requirement in today’s health- and disease-related news and current affairs stories (Figenschou, 2017). With the rise of digital and social media, involving blogs and online accounts dedicated to the self-narration of patients with stories of life with illness to tell, the research focus on patients’ experiences has intensified further (Conrad, Bandini, & Vasquez, 2016; Stage, 2017). This transition from a more traditionally authoritative, expert-based coverage of health toward a focus on the afflicted individual is duly noted in the research literature. At the same time, there is a relative lack of studies that explore the motives and strategies, rewards, and costs involved for people who disclose their experience with illness over time via

Espen Ytreberg: espen.ytreberg@media.uio.no

Kjersti Thorbjørnsrud: kjersti.thorbjornsrud@samfunnsforskning.no

Date submitted: 2020–01–06

Copyright © 2020 (Espen Ytreberg and Kjersti Thorbjørnsrud). Licensed under the Creative Commons Attribution Non-commercial No Derivatives (by-nc-nd). Available at <http://ijoc.org>.

the myriad formats in the current hybrid media landscape. This may partly reflect a modest interest in the experiences of laypersons exposed in the media in general (Palmer, 2017).

As a category of media participant, medical patients tend to be attributed a high moral status. It is a widespread assumption in popular debate and scholarly studies that sharing in the media what it is like to be afflicted with disease is an act of goodness: It helps society overcome ignorance and stigmatization at the same time as it offers the opportunity to help oneself heal (Blaker, 2013; Schudson, 2015). This high moral status makes patient-participants a standout case in the context of today's media participation. In the case of reality TV, which has led the current trend toward increased media participation from the 1990s on, research on its audiences has demonstrated that it is common to impute a "wannabe" (Hill, 2007, p. 119) mentality and questionable motives for "acting up" (Hill, 2007, p. 192) to participants in this genre. The genre of the news and current affairs interview with so-called "ordinary people" could be considered neutral in terms of the moral status of nonprofessional participants; this genre implicitly raises participants to the status of a credible, if circumscribed, public voice. At the same time, that voice is usually based on witness status or on being implicated in a newsworthy event rather than on moral affirmations (Palmer, 2017; Peters, 2001).

Patient-participants provide a case of high moral status that has been less researched than other genres. It should be said that not all diseases are connected to a high moral status; those suffering from sexuality- and lifestyle-related diseases have, for instance, traditionally been at risk of blame. In the main, however, medical patients are accorded the status of innocent sufferers with a right to receive sympathy for their hardship (cf., Seale, 2003). Suffering from illness is a misfortune that may render the patient communicatively incapacitated; however, at the same time, illness can bring certain communicative advantages. The personal account of suffering from disease seems to carry a particular rhetorical weight because it comes from a place of blameless suffering and has the particular authenticity of being expressed in the first person. A key question for investigation, then, is whether the role of being a "good participant" is connected to particular forms of experience and agency in media participation.

In this article, we investigate how the experiences and agencies of patient media participation are articulated over longer spans of time and across media. Based on 18 interviews with Norwegian patient-participants, the article explores some key themes that emerge when considering patient media participation in the longer term. *Longer term*, here, means media participation that extends beyond one-off media exposure and becomes an ongoing media engagement lasting several years. Generally, the longer term has not been analyzed much in existing media participation research, and both agency and experience may often best be considered as accumulating gradually with repeated media participations. Moreover, exercising control over the selection, dramaturgy, and nuances of a storyline can be very different when an illness is acute compared with sharing the mature experience of living with a disease over time (Frank, 2013).

Our emphasis on participation that crosses media and formats follows from the fact that with today's plethora of media platforms composing both mass and social media, the expression and performance of illness have become sustained far beyond one-time media exposure. As recent research suggests, repeat (i.e., serial) media participation has become common, as has so-called "career" media participation, which crosses over into a professional or semiprofessional form of media work. A range of studies has analyzed

blogs and social media accounts (e.g., the overview in McCosker & Darcy, 2013), although only a very few have explored the motivation of the contributors themselves (e.g., Orgad, 2005; Ytre-Arne, 2016; Ytreberg, 2019). Limited attention has been paid to how this type of media participation is entangled with participation in traditional mass media and how media performances, postings, and responses cross boundaries between professionally produced formats in the mass media and user-generated content on social media, creating what Chadwick (2013) terms a *hybrid media system*. Different media platforms, formats, and genres offer patient-participants significantly different options and limitations; it seems plausible that agency and experience will both be articulated over time as patient-participants find a trajectory through this hybrid media system.

The article investigates the investments patients hold in their participation when seeking the media, patient-participants' relationship to their personal audiences, issues of self-disclosure in the moment or retrospectively, their attendant dilemmas, and their negotiations of agency. We end with a discussion of when patient-participants terminate their participation and some limitations of the openness ethos that motivates them to seek the media in the first place.

Patient Participation: Power, Agency, and Experience

The high moral status of the layperson who shares her experience with disease in the media can be linked to grassroots citizen groups and the women's movements in the 1960s and 1970s. At that time, the sharing of experiences with illness through the media became a tool both for opposing traditional, authoritative medical regimes and for working against dominant perceptions of illness as something to be endured in silence and isolation (Schudson, 2015). Celebrities were forerunners in this use of media, opening up about afflictions ranging from cancer to alcoholism to dyslexia (Brown & Zavestoski, 2004; Brown et al., 2004; Klawiter, 2004). Gradually, they were followed by accounts from ordinary people struggling with illness. Activism and campaigns related to, first, cancer and, later, HIV became models for other patient groups that propagated openness and fought stigma. On the tail of these developments, the layperson with an illness became established as a distinct category of media participant. In this process, the initial political force of nonprofessional participation has been less distinct when compared with its activist origins. The belief in the value of sharing and openness related to health has become mainstream and relatively depoliticized; popularized psychological notions of the therapeutic value of disclosure now serve to legitimize a range of media formats focused on personal experiences of illness and the perceived goodness of those who tell them (Wright, 2008).

Before the rise of social health movements, the communication on illness was assumed to be based on a hierarchical model of medical authority, with the patient as a passive receiver of expert advice, as argued by Briggs and Hallin (2016) in *Making Health Public*, which has been important for establishing research in health and the media as a field. This model has, at least in part, been replaced by patients playing a more active role as citizens or consumers, the latter typically through service journalism. Briggs and Hallin point out that in both citizen and consumer modes, experiences with illness are often told through human-interest stories. They use the notion of "coproduction" (Briggs & Hallin, 2016, p. 13) in which health news is seen as the result of an amalgamation of media logics and media professional requirements on the one hand and the strategies and rationale of various actors from the health field on the other. An empirically

informed exploration of lay participants' perspectives and strategies is largely absent from Briggs and Hallin's writing. It seems clear, however, that the sick person and the medical patient have joined the ranks of the media as coproducers, defined as ordinary people placed in the extraordinary circumstances that media construct (Syvertsen, 2001).

Although there is a long history of lay participation in mass media (Ekström, Jülich, Lundgren, & Wisselgren, 2010), research attention increased as opportunities for participation expanded, beginning in the 1990s, following the spread of reality TV and talk shows featuring "ordinary people" (e.g., Gamson, 1998; Hill, 2005; Livingstone & Lunt, 1994; Ouellette & Hay, 2008). Written before the plethora of digital and social media arrived, this research addressed patient participation, particularly in therapeutic talk shows, and made important points about the power mechanisms of media participation that may work against ideal beliefs in the goodness of sharing for the patient who relates personal experience for fellow sufferers and the larger society. The basic communicative ideal, as voiced prominently by Frank (2013) in the context of early medical humanities, was that, for the sick individual, expressing one's story is an act of reclaiming control. For Frank, finding the subjective truth about what this situation entails involves not only coming to terms with and accepting a life marked by illness, but also opposing the patient's role that is traditionally assigned by medical experts or predefined popular prejudices. This belief in the value of sharing personal experiences has been tempered by research that critically examines the tendency for dominant media narratives to narrow and distort the reality of persons afflicted by disease. Examinations of therapeutic discourse in television programs featuring ordinary people as participants have pointed to the fact that ideal ambitions of expression and patient empowerment might have a hard time if they run counter to the demands of media industries (e.g., Blaker, 2013; Grindstaff, 2008; Shattuc, 1997; White, 1992). Ostensibly, such programs are about personal healing and they build a mediated discourse that facilitates it, but therapeutic TV involves significant self-exposure under circumstances of highly unequal power that favor the producers' interests. Other media research points to a tendency for patient stories to be appropriated by commercialized and corporatized patient organizations, which reformulate these stories into narrow schemata of positivity and heroic struggle; complex phenomena of illness and health may be reduced to a binary opposition of sick versus healthy (Ehrenreich, 2001; Frank, 2009; King, 2004; Seale, 2003).

In a valuable in-depth study of how ordinary people experience being exposed in the news media for the first time, Palmer (2017) points to the basic asymmetry between media professionals and laypersons to explain why some participants feel estranged when they see their story reframed and published. Even if reporters take care to treat their subject fairly and compassionately, they also and by necessity have an instrumental interest in producing a story that attracts an audience. With regard to the patient-as-participant category, such diverging interests are likely to come into play because the patient first needs to get well, whereas, for instance, the TV producer primarily needs an appealing and competitive program. This is a reminder that although the role of being a "good participant" may have its advantages and allows for particular forms of agency, power over media participation is still likely to be unequal, favoring media formats, genres, and professions.

With the advent of user-generated social media, the increasing focus on personal stories in mass media has been followed by an explosion of mediated personal illness experiences (Conrad et al., 2016). Blogs, chatrooms, and social media posts have become arenas for communicating personal experiences,

giving advice on treatment, and sharing a spirit of fellowship and solidarity. As in the case of reality TV and talk shows, expressing individual experiences of illness in social media has been described as a way for afflicted persons to reclaim control over their personal voice and story. As opposed to appearances in traditional mass media formats, where production settings and framings are in the hands of professional reporters and producers, social media arguably leave the contributors with more agency in the telling of their stories, including what gets emphasized and what is left out (McCosker & Darcy, 2013; Orgad, 2005; Ytre-Arne, 2016). It is worth noting, however, that social media and blogs leave the individual with increased personal responsibility for how they appear and what they expose. In professional news media, ethics codes direct journalists to protect vulnerable individuals from exposure in certain circumstances. These include cases in which individuals are deemed unable to judge the consequences of being exposed in the media or are incapable of assessing their performance's impact (Larssen & Hornmoen, 2013). Moreover, whereas participants in social media decide what to post and when, they do not control the spread, response, or longevity of messages that remain searchable and accessible for an unlimited time.

Within the tradition of media participation research, the possibilities and limitations of participants' agency have also been much discussed on a general, theoretical level—for instance, the character of power in media's production of participation, the notion of empowerment and subversion (e.g., Fuchs, 2011; Hesmondhalgh, 2019; Jenkins, 2006). These debates have to some extent been fueled by broader ones about the Internet and digital media as empowerment tools. Today, those hopes have become rather distant, whereas limits to agency in digital environments have moved to the center of the agenda. Although it has become evident that agency turned out to be very much limited in digital contexts, it may also be time to provide more empirically grounded examinations that start from the premise that agency in media participation is first and foremost contingent, to articulate the factors it is contingent on, and to examine the resulting experiences. Looking back on the social health movements of the 1960s and 1970s, it seems clear that patients' experiences are vitally important to understanding participation as a wider, societal phenomenon and are worth investigating more fully today. Understanding how participation is experienced does not run counter to understanding media power mechanisms; on the contrary, it can give us a fuller understanding of how such mechanisms work and what they mean for those who are caught up in them.

Method

This study's informants were selected with a view to presenting a range of illnesses and media engagements wide enough to provide the basis for an exploration of some key themes of media participation in the long term. Some interviews were also carried out with informants whose media exposure was of shorter and more limited duration. For the purposes of this article, however, we include only informants whose media exposure lasted from half a year up to 10 years and included numerous media appearances. All informants appeared in both mass and social media. Among those interviewed were also informants who had long-term contact with the media because of also having professional backgrounds in the media or in health organizations with regular media contact.

Most of the informants (i.e., 12 of 18) were women, reflecting the overrepresentation of women as patients in the media. Younger people affected by disease were also disproportionately represented in both mass and social media, and this is reflected in this study's group of informants, who varied in age from early

20s to middle age. As for the diseases represented in the study, the informants were selected with a view to finding groups of patients who attract substantial media attention while also representing a wide range of diseases in terms of status or stigma (Album & Westin, 2008). Thus, the informants consisted of two main patient groups: cancer and mental illnesses. Cancer has probably received most attention in the media in recent decades, and those afflicted are represented by strong and well-organized patient organizations. Mental illnesses have moved from stigma to openness only recently, but are now receiving extensive media attention. Both mental illnesses and cancer cover a wide range of afflictions, including subtypes still marked by stigma and silence. Generally speaking, however, mental illness patients are considerably more vulnerable to societal prejudice. Our informants represented both ends in each group, ranging from breast cancer to colon cancer and from anxiety and depression to anorexia and personality disorders.

The interviews lasted one to two hours, based on semistructured interview guides. Two informants were interviewed more than once. The interview guide focused on types of media participation, motivations for sharing stories of illness in the media, experiences with different types of media and media professionals, and developments in the informants' practices and evaluation of their media participation over time. All interviews were recorded, transcribed, and coded using software. We conducted the coding and analysis of the interviews following the thematic focus of the interview guides and the systematization of new themes that appeared in the empirical material. Codes were constructed, split, and merged based on the aspects they illustrated. We translated all quotes in the analysis from Norwegian into English.

Results

Seeking the Media

Previous research has indicated that the stated motivations behind the media participation of people with an illness tend to be idealistic. These motivations include the desire to be open about one's illness and at the same time to provide information to the public; in social media, there is also the motive to provide a forum for exchange, mutual support, and acknowledgment (Thorbjørnsrud & Ytreberg, 2020). All informants in this study shared their experiences in several media outlets and platforms over a certain time span. They shared a strong motive to describe something important, something that feels true to them, and to tell it in a way that does the story justice. When asked about their motives for wanting to participate, most informants emphasized being open about their situation with illness as a basic motive. Openness is about baring one's inner self as a sick person (i.e., one's intimate spheres and spaces), but it is also an attempt to reach out, connect with, and be of help to others. One informant with a cancer diagnosis said it thus:

I do it for those who cannot do it themselves. I remember the first time [name of TV channel] asked me for an interview. I thought, "Oh, can I manage that? Will I overcome being in the middle of all that?" Then I thought, "Well, we are all worn out but yes, if someone has to do it, I have the guts it takes." That's the difference. I am not afraid of stepping forward, speaking about it, being open about it, and so I have to take it on, on behalf of everyone else.

The informants varied with regard to their age and illness stage when they started communicating about their disease via media. For some of the very youngest, who were in their early teens when they first expressed their experiences and feelings about illness, a key motive was attracting attention to their suffering and seeking an acknowledgment of it. Through attention, they sought help to cope with life. This was the case for a teenager who participated in a documentary series about youth struggling with mental illnesses:

At the time, school was no good, I did not have any friends in class, I did not know how to fix my life. When I decided to apply for a role in the program and showed up for an interview with the program producers, what I needed was attention, basically.

Looking back, she found that the type of attention she received from this participation was not what she needed; rather, her persona as it appeared on screen after editing made her feel deeply estranged and anxious. Other informants, who also entered the mass media in their late teens, gave the impression of being more prepared for the dramaturgy of television, although the casting involved a simplifying and skewing of their histories of illness. As long as they found the "type" they were set to represent reasonably relevant or adequate, they seemed rather at ease with it, even if this resulted in a rather selective representation. Even if they were personally inexperienced with massive media exposure, these informants gave the impression of possessing a type of media competency and role consciousness often associated with media-savvy digital natives. Their first appearance on television was preceded by extended experience profiling themselves on social media and blogs, and they were somewhat familiar with the posing, filtering, and editing involved in the construction of a media persona.

For older informants, going public in the media was more often based on quite careful deliberation, often long into their trajectory as a patient, as in the case of this middle-aged cancer patient:

In the first 4–5 years, I only talked to my closest family. I had no desire to become public. During the first years, I wrote as a therapy, but only for my own sake, as a way to understand the situation I was in and the most painful parts about being ill. I did not share these texts with anyone, not even with my family. Partly because it was painful, partly because I was wary of talking in bits and pieces. I needed a big format to create a wholeness.

It was only after having written a book about his experiences of the long-term effects of cancer treatment that this informant became the face of awareness campaigns and began appearing in news media and magazines. He explicitly stated that he did it to help others in similar situations, not for himself. From being very reluctant about appearing in the media, he loosened up on those self-restrictions after making the decision to represent others. This was something of an exception in the interview material; however, most of our informants described a development where they established a sense of control over their appearance in the media more gradually over time.

Building a Personal Audience

Among the informants, only one reported receiving concrete negative responses following media participation. It is probably no coincidence that this is an individual with a low-status mental illness. For the

great majority of patient-participants, the experience of participation was one of affirmation, positive responses, empathy, and encouragement, whether the appearance commented on was via mass or social media. What one may call a personal audience is built over time, an audience with an attachment to the participant's life with illness, by virtue of that participant's repeated media appearances. The participant's circle of family and friends may be involved in this personal audience in addition to others in the participant's lifeworld, those who are themselves afflicted by the disease or know well someone who is, and those who feel strongly and personally affected by the participant's story. One informant with mental illness said this about the advantages that media participation can bring to the participant's social standing vis-à-vis friends and schoolmates:

I had no problems at all [with responses to the participation]. I think I almost got more respect. Only my immediate circle of perhaps five friends had known what I went through with my illness. And the 20 other people in my class had been thinking I was just an ordinary person who was a bit quiet, whereas the five knew that I used to be an entirely different person. And the 20 who did not know me [before seeing the TV program aired] gained a great respect for me then.

This attention was the result of mass media participation, the kind of television program that affords large-scale exposure and visibility.

Although the great majority of our patient-participants described a positive relationship with their personal audiences, several also mentioned various stresses and strains emerging over time. Several informants reported that they had gained some distance from their suffering over time after they had initially opened up in media participation, but then they would then receive messages from personal audience members who were themselves in the middle of the same suffering. A cancer informant was pulled back in time to rawness and desperation by such messages:

Because of the content that's out there, I suddenly am approached by people who have just received their diagnosis and are completely out of it, maybe they have small children, they're writing long messages to me about all of this. I always answer, or I try to point them to places where they can talk to someone. . . . But I feel how much that kind of thing affects me. Things like doing a talk I can have a more professional relationship to, but when I hear about people who are in the place I used to be, all those emotions come back, and it takes some time to get back out of that again.

Here, several strains combine to make audience response hard for the patient-participant to handle. The participant now has to live with a disconnect vis-à-vis the personal audience that gets in the way of previous feelings of closeness. This informant's reference to a persistent situation of "content that's out there" is a factor that came up in many interviews. With digitalization, not only social media content but also mass media content are available and searchable in digital archives. Participants have to live with the fact that footage of themselves when they were very ill can command new attention and new audiences via digital archives or reruns. When this happens, participants may find themselves resistant to taking on this mediated version of themselves, what Palmer (2017) calls their "partial, circulating self" (p. 133). One young

mental patient informant was generally glad that he had participated in a documentary television series, but he still felt vulnerable. He found strategies to protect himself from traumatic memories when the episodes were broadcast, both in the first showing and during reruns. From his surroundings, reactions were positive, but even so, he considered it harmful for him personally to watch the documentary because it tied him to a darker past he wanted to leave behind:

I did not watch the episodes when they ran on television. I did not want to because . . . firstly it evokes so many memories. I don't know, it just feels strange to realize that this is me. It is just a bit unpleasant to think about that I have actually been there. I had started feeling better about things again. I tend to forget how bad it was, and if I watch it, I almost feel, how to say it, almost nostalgic? And then I start thinking that this is how it really is, that this is how I am all the time. That I am doomed to be like this, it will never end.

Disclosure in Retrospect

A key choice for the informants in our study was whether to disclose painful and harrowing particulars of their experience with illness at the time of having the experiences or in retrospect. Here a mental patient spoke for the latter choice, which was more common among the informants:

When you are really down, I don't think you are that good at communicating, and it can be hard to be honest. You can only gain an objective perspective on yourself when you're a bit better. You have to distance yourself in order to look at yourself and your psyche.

Here, retention and the view in retrospect guaranteed both the dignity of the participant and the communication of something worthwhile to the audience. Another informant recommended trying to imagine before participating how it would come across 10 years in the future. Here, the logic was one of temporal protension instead of retention, but the basic premise was the same: Moments of deep suffering cannot and should not be the moments of greatest self-exposure. In the words of another informant looking back over several years, patient-participants are not themselves in such moments:

I have been thinking that back then, I kind of wanted people to know how I was feeling inside. In retrospect, I can kind of understand that need. But I also know that I had this immense need for affirmation, for someone to care about me and see me for who I was. I hadn't had too much of that in my life. And those kinds of needs can maybe take charge a bit too much. . . . On my worst days, I still have them, sometimes I still get to thinking about writing or sharing something. And then I am like, "You're not yourself now. Maybe you should talk to a friend," you know?

The informants who favored self-disclosure in retrospect reported feeling that they were too young and inexperienced to realize the significance of their actions at the time of their first media appearances and sometimes too afflicted by illness to have the capacity to make sound judgments. Also, some highlighted the risk that illness can weaken one's judgment in the moment. This point was made by informants with somatic and mental illnesses alike, as expressed by one informant with a mental disorder: "Those who are

cured are more ready to make that decision, whether they are ready to talk about it, when they have worked through their illness.”

These informants perceived an inbuilt or latent conflict between the impulse to self-expose and other important considerations, such as audiences’ chances for a real benefit and the participant’s own need to keep something in what Meyrowitz (1985) termed the *deep backstage* (p. 46). The reluctance toward immediate exposure of illness in the present tense is also related to the nature of serious illness, which, in a basic sense, is about a loss of agency. The gravely sick person is, at least in part and for a while, taken over by a body or mind that refuses to function. As a defender of the personal expression of illness in public as a conduit to personal healing and solidarity, Frank (2013) sees this stage of illness as untellable (i.e., as “antistories”). He argues that these tend to be stories dominated by chaos and lacking hope, meaning, or a sense of order. They are not only painful to listen to, but also provide little relief or redeeming insight for the suffering person.

Another interesting case is the cancer informant who, in our first research interview was very positive both about how she was portrayed in different media outlets and campaigns and for the feedback she received. She told us that being picked out as a valuable exemplar and the personal face of a large-scale awareness campaign made her feel that she was mastering a new skill. Even though illness had made her unable to do her original job, she found that she was good at something else: communicating via media and reaching out to an audience. A year later, however, she asked for a second interview. She had become ambivalent about her media performances and expressed a certain disappointment with the patient organization that had used her in their campaigns and pitched her story to journalists. She now had the impression that the organization was more reluctant toward her, referring to the importance of not “overusing” her as an exemplar in the media. Her latest media engagements, with the patient organization as the mediator, had involved less prestigious outlets. To her, this felt like a devaluation and trivialization of her experiences:

I have been open to taking on new responsibilities, and I was thinking I could be a voice who reached the sponsors of the organization, giving talks to different stakeholders. And I said yes when they asked me to give an interview to a COOP (a member-owned business), I was just like, “Yes, of course, I will help out again.” And then I realized that I was to figure in a free magazine in a COOP supermarket, in a grocery store, you know. And then I was like, “OK, my cancer experiences alongside the milk cartons.” I actually regret doing that a bit.

Although this informant also had career-related reasons to reconsider her media participation, her dislike of the trivialization of her story resonates with other informants’ experiences. Opening up about illness requires emotional work and investment, and the informants in our study believed their stories should mean something beyond mere pastime or entertainment.

Practices of long-term reflection were referred to by several of the informants as a means to recover control and a measure of distance. One informant with a cancer-related disorder not only thought self-restrictions on disclosure were important, but also had formulated a set of rules for that purpose:

I had some rules set from the very start. The first one was that I needed to believe what was published was something my kids would be comfortable reading in 10 years, because when something goes online, it is always going to be available. Also, I needed my husband to read everything and greenlight it. And then I would avoid making anything public when I was very caught up in a situation or emotionally disturbed. In that case, I would wait a while before publishing so that I could digest things and give them a second consideration.

This informant would qualify as media-savvy and relatively well equipped to avoid overexposure. In this article's context, it is worth noting how extensive the social and temporal advance planning required is in this informant's eyes. It becomes the participant's job and not the job of media professionals to produce something like 10-year foresight. The emphasis on holding back on exposure was accompanied for one informant with a cancer diagnosis by the more general view that media omnipresence in everyday life will push people in the direction of disclosure: "We expose ourselves too much and are too open. We don't think much about consequences, it's become so common for people to expose themselves on social media and blogs; people go along with anything."

Disclosure in the Moment

Although most informants tended to favor disclosure in retrospect, some told of an impulse to self-expose via media in or very close to moments of being sickest and suffering the most. At a quite basic level, media may be used as an aid when patients try to process what is happening to them, both cognitively and emotionally. One mental patient informant spoke half apologetically about how she sometimes recorded herself without thinking of distributing the recording:

I have caught myself filming if I am down, just because I need to talk to someone who doesn't really respond and can't think. It's just really nice to be able to talk in that way. It's not that I am looking at those tapes afterward. It's just good to get it out there and then.

When such basic processing by means of media is not only recorded but also distributed, several risks are added. Although such risks can clearly be very real, there may also be advantages to such self-exposure. Another mental patient informant who had both appeared on television and maintained a social media channel reflected on the demands of self-exposure in the current context of media saturation and social media proliferation:

I have published images that have been plenty about saying, "Yeah, wow, I made it." I was coming across in social media as having a great time. But then I just had enough, I was like, "I'm done with that, all the façade stuff, from now on I just have to be faithful to myself and my feelings, I just have to tell it like it is" . . . and so I wrote it all down, I said, "Hi everybody, everything you've seen on the channel, that's just all bullshit. I've only been pretending. I'm really feeling like crap. You don't have to feel sorry for me or anything like that, but I just want to say, 'If someone out there is feeling like this, you're not alone.'" And then it was out there.

Here, a belief seems to be expressed that the present plethora of self-presentations in social media and the image constructions they involve are a tangle that has to be cut through by a definitive act of self-exposure. The vulnerability of that act was precisely what seemed to make it real and meaningful in the eyes of this informant. A main challenge, then, is how to combine the existential impulse to reach out in the moment with notions of privacy and dignity that may require consideration over time.

At a basic level of human temporal experience, it may be questionable whether a tidy opposition between disclosure in the moment and in retrospect captures the reality of being a participant—at least a serial or career participant. The act of sharing publicly something as affecting as serious illness is itself one that may easily start working on the participants' perception of themselves, their illnesses, and the act of sharing. This process can be used by the participant, although the given medium, format, and genre may set limitations. Thus, participation may be a tool for the care of the self in Foucault's (1994) sense, or for what he terms *self-writing* in the case of social media messages and blog posts. For one informant, a quite fundamental form of self-realization was involved when she participated in a television series about living with mental disorders:

I think I had such a problem for many years with knowing who I was as a person, so that I have felt that the impression I give wasn't always right or was different from how I really felt sometimes. So I believe it helped me to tie things together and sort of dispose of the version of me that makes people expect me to manage everything. That's why it has been a good thing for me to be open about things that were difficult. And for me it has almost been easier [to participate in media] than to sit down and talk, since I haven't been good at talking to people, and close relations have been hard for me. So it has almost been easier that people just learned about it that way some years ago than if I had to tell them face-to-face.

Shutting Down Participation

Not only did many of the serial participants in our sample have to understand and meet the requirements of different media, genres, and formats, they also had to deal with the fact that their view of the participation itself may change as they gain greater life experience. Several informants reported that they gained an overall perspective on their participation only after doing it for a longer period of time. Several also came to regret the extent of their self-exposure when looking back on it after that period in their lives was over. An example is this mental illness patient, who used to write a blog in her early teens: "I have tried my very best to hide those posts, actually, especially with a view to my studies and my further career and such."

Participating in the media could be seen as walking a line between opening up and holding back. Several informants changed how they evaluated this balancing act over time. In several cases, reevaluation came when informants were closing a period of participation to move into a period of life marked by other priorities. Looking back, these informants reflected on how much to share in the present as an ongoing process versus how much to divulge in retrospect. An informant with cancer pointed to the fact that the sharing that happens continually on blogs and other social media is not necessarily more self-disclosing or

more accurate than that done in retrospect (i.e., when the illness is no longer acute). This informant published a book at the end of her period as a serial participant and saw it as an opportunity to make a onetime, more comprehensive, and more open statement:

It's much easier to talk about the hard things when you're finished with them than while they are happening to you. So I think I have emphasized the positives more in my blog than in the book in order not to scare those around me so much, to reassure them in some way. But in the book, I can say how hard it was. Now it's over, so now it's okay, you know.

Several informants, at the time of being interviewed, had reached a point when they wished to withdraw from being a media participant either temporarily or altogether. A main motivation was the risk of becoming permanently associated with the disease and the patient role. As one informant said of her disease: "That's the negative thing [with being a media participant]—you can get branded with it." This is a resistance to being stuck in the role of "patient," in having one's identity be permanently derived from one's illness. This can come to be perceived by participants as being stuck in time and deprived of a chance to develop both personally and professionally. It can also carry a stigma if outside expectations are that the disease is a temporary affliction or not serious, for instance, or if it does not readily show, as can be the case with mental illness. One former mental patient said of the experience of coming forward about mental illness in the media,

I don't think all sick people are able to leave that off; they become attached to their anxieties and the depressive identity they have spoken about in the media. And so they end up living forever as that person they communicated in the media back then. If you're not the kind of personality who is able to close that chapter in your life, then I don't think it's good for you to expose yourself in the media as someone who struggles mentally.

Discussion: The Limits of Openness

Underlying the accounts and experiences expressed by the informants in our study was an ethos of openness that we perceive to be characteristic of the patient-participants' role. To them, coming forward, sharing, and connecting with audiences is good because it promotes a wider knowledge and understanding of what it is like to be seriously ill. In many ways, their experiences with media exposure bear this out. Not only did they report audience response as overwhelmingly positive, allowing participants to build over time what we have termed a *personal audience*, which brings affirmation and feelings of mutual rapport, but also several informants reported feelings of achievement, even if their control over the terms of exposure was limited. Most of our informants conveyed a sense that participating in the media to tell their stories of illness and life was worth doing, that the advantages were real, and that the stresses and strains—if also real—were manageable.

At the same time, we have demonstrated that the high moral status of patient-participants did not insulate them from experiencing stresses and conflicts. For some, primarily those who dealt with mainstream mass media, a lack of perceived agency led to a certain disillusionment. For others, particularly in social media contexts, the demands of being supportive and understanding toward audience members had

stressful sides. Then, there was the basic problem of how to handle the loss of agency inherent in serious illness itself, which produced the dilemma of whether to self-expose while suffering or hold out for the benefit of hindsight and maturity.

Although the ideal of openness carries great moral authority and is key to the self-narrations of many participants' experiences, we want to suggest by way of conclusion that it may also have its limits. We have suggested elsewhere (Thorbjørnsrud & Ytreberg, 2020) that the health organizations that often help the media recruit patient-participants work from a notion of moral alignment with patients that is, that they want the same thing: to help the sick. Journalists and other media professionals may be influenced by similar feelings of alignment despite ideals of journalistic autonomy vis-à-vis sources. Paradoxically, this may leave patient-participants more vulnerable if interests begin to diverge (i.e., if a journalist or patient representative wants to have the patient self-expose to a degree that the patient then regrets). In other words, the ethos of openness may come to serve the interests of organizations more than the patient-participants themselves. In other circumstances, the same ethos may serve participants, but not necessarily audiences. The notion that being open and sharing about illness helps others and promotes insight and understanding is a premise that goes largely unexamined. For a few informants, the belief that learning about their illnesses would positively affect audiences' lives waned with the passage of time. One informant said this about having blogged about mental illness over a number of years:

I did it quite a lot when I was younger, but in retrospect I regret some of the things I wrote then, really. . . . I was very, very sick when I wrote that blog. It was just a very bleak, sick person's perspective without much hope. There and then that writing was enormously therapeutic for me, but I don't believe it did the readers any good, really.

References

- Album, D., & Westin, S. (2008). Do diseases have a prestige hierarchy? A survey among physicians and medical students. *Social Science & Medicine*, 66(1), 182–188.
- Blaker, L. (2013). It's good to talk? Talking cure and the ethics of on-screen psychotherapy. *Journal of Media Practice*, 14(3), 193–209.
- Briggs, C. L., & Hallin, D. C. (2016). *Making health public: How news coverage is remaking media, medicine, and contemporary life*. London, UK: Routledge.
- Brown, P., & Zavestoski, S. (2004). Social movements in health: An introduction. *Sociology of Health & Illness*, 26(6), 679–694.
- Brown, P., Zavestoski, S., McCormick, S., Mayer, B., Morello-Frosch, R., & Altman, R. C. (2004). Embodied health movements: New approaches to social movements in health. *Sociology of Health & Illness*, 26(1), 50–80.

- Chadwick, A. (2013). *The hybrid media system: Politics and power*. Oxford, UK: Oxford University Press.
- Conrad, P., Bandini, J., & Vasquez, A. (2016). Illness and the Internet: From private to public experience. *Health, 20*(1), 22–32. doi:10.1177/1363459315611941
- Coward, R. (2013). *Speaking personally: The rise of subjective and confessional journalism*. Houndmills, UK: Palgrave Macmillan.
- Ehrenreich, B. (2001, December). Welcome to cancerland. *Harper's Magazine, 303*(1818), 43–53.
- Ekström, M., Jülich, S., Lundgren, F., & Wisselgren, P. (2010). *History of participatory media: Politics and publics, 1750–2000*. London, UK: Routledge.
- Figenschou, T. U. (2017). Patient narratives: Health journalists' reflections, dilemmas, and criticism of a compelling journalistic tool. In B. K. Fonn, H. Hornmoen, N. Hyde-Clarke, & Y. B. Hågvær (Eds.), *Putting a face on it: Individual exposure and subjectivity in journalism* (pp. 235–256). Oslo, Norway: Cappelen Damm.
- Foucault, M. (1994). *Ethics: Subjectivity and truth*. New York, NY: Free Press.
- Frank, A. W. (2009). Tricksters and truth tellers: Narrating illness in an age of authenticity and appropriation. *Literature and Medicine, 28*(2), 185–199.
- Frank, A. W. (2013). *The wounded storyteller: Body, illness, and ethics*. Chicago, IL: University of Chicago Press.
- Fuchs, C. (2011, May 13). Against Henry Jenkins. Remarks on Henry Jenkins' ICA talk "Spreadable Media" [Blog post]. Retrieved from <http://fuchs.uti.at/570/>
- Gamson, J. (1998). *Freaks talk back: Tabloid talk shows and sexual nonconformity*. Chicago, IL: University of Chicago Press.
- Grindstaff, L. (2008). *The money shot: Trash, class and the making of TV talk shows*. Chicago, IL: University of Chicago Press.
- Hallin, D. C., Brandt, M., & Briggs, C. (2013). Biomedicalization and the public sphere: Newspaper coverage of health and medicine, 1960s–2000s. *Social Science & Medicine, 96*, 121–128.
- Hesmondhalgh, D. (2019). *The cultural industries* (4th ed.). London, UK: SAGE Publications.
- Hill, A. (2005). *Reality TV: Audiences and popular factual television*. London, UK: Routledge.

- Hill, A. (2007). *Restyling factual TV: Audiences and news, documentary and reality genres*. London, UK: Routledge.
- Hinnant, A., Len-Ríos, M. E., & Young, R. (2013). Journalistic use of exemplars to humanize health news. *Journalism Studies*, 14(4), 539–554. doi:10.1080/1461670X.2012.721633
- Jenkins, H. (2006). *Convergence culture*. New York: New York University Press.
- King, S. (2004). Pink Ribbons Inc.: Breast cancer activism and the politics of philanthropy. *International Journal of Qualitative Studies in Education*, 17(4), 473–492.
- Klawiter, M. (2004). Breast cancer in two regimes: The impact of social movements on illness experience. *Sociology of Health & Illness*, 26(6), 845–874.
- Larsen, K., & Hornmoen, H. (2013). The literary journalist as a fellow human being. *Literary Journalism Studies*, 5(1), 79–93.
- Livingstone, S., & Lunt, P. (1994). *Talk on television: Audience participation and public debate*. London, UK: Routledge.
- McCosker, A., & Darcy, R. (2013). Living with cancer: Affective labour, self-expression and the utility of blogs. *Information, Communication & Society*, 16(8), 1266–1285. doi:10.1177/1471301218768162
- Meyrowitz, J. (1985). *No sense of place: The impact of electronic media on social behavior*. New York, NY: Oxford University Press.
- Orgad, S. (2005). *Storytelling online: Talking breast cancer on the Internet*. New York, NY: Peter Lang.
- Ouellette, L., & Hay, J. (2008). *Better living through reality TV: Television and post-welfare citizenship*. Oxford, UK: Blackwell.
- Palmer, R. (2017). *Becoming the news: How ordinary people respond to the media spotlight*. New York, NY: Columbia University Press.
- Peters, J. D. (2001). Witnessing. *Media, Culture & Society*, 23(6), 707–724.
- Schudson, M. (2015). *The rise of the right to know: Politics and the culture of transparency, 1945–1975*. Cambridge, MA: Harvard University Press.
- Seale, C. (2003). Health and media: An overview. *Sociology of Health & Illness*, 25(6), 513–531.
- Shattuc, J. (1997). *The talking cure: TV talk shows and women*. New York, NY: Routledge.

- Stage, C. (2017). *Networked cancer: Affect, narrative and measurement*. London, UK: Palgrave Macmillan.
- Stroobant, J., De Dobbelaer, R., & Raeymaeckers, K. (2018). Tracing the sources: A comparative content analysis of Belgian health news. *Journalism Practice*, *12*(3), 344–361. doi:10.1080/17512786.2017.1294027
- Syvetsen, T. (2001). Ordinary people in extraordinary circumstances: A study of participants in television dating games. *Media, Culture & Society*, *23*(3), 319–337.
- Thorbjørnsrud, K., & Ytreberg, E. (2020). A human interest economy: The strategic value of turning ordinary people into exemplars in the news media. *Journalism Studies*, *21*(8), 1093–1108. doi:10.1080/1461670X.2020.1720520
- White, M. (1992). *Tele-advising: Therapeutic discourse in American television*. Chapel Hill: University of North Carolina Press.
- Wright, K. (2008). Theorizing therapeutic culture: Past influences, future directions. *Journal of Sociology*, *44*(4), 321–336.
- Ytre-Arne, B. (2016). The social media experiences of long-term patients: Illness, identity, and participation. *Nordicom Review*, *37*(1), 57–70. doi:10.1515/nor-2016-0002
- Ytreberg, E. (2019). Control over stories of illness and life: The case of a career media participant turned media professional. *Nordicom Review*, *40*(2), 37–48. doi:10.2478/nor-2019-0023