

TV Inside the Psychiatric Hospital: Patient Experiences

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This study investigates patients' experiences with participating in a television (TV) documentary series filmed within psychiatric hospital wards. The study relies on interviews with patients, health staff, and TV producers, and asks how access is negotiated and how patients experience different phases of the production process. Based on a discussion of health ethics versus journalistic ethics, and the particular relations of power asymmetry and dependence within a health institution, the study concludes that a discourse emphasizing the benefits of openness worked to overshadow the need for extra sensitivity and care for the most vulnerable patients. Most patients appreciated the opportunity to share their experiences of illness and hospital treatment, but the increased strain on patients who were negatively affected by exposure calls for renewed attention to what informed consent and autonomy imply when media professionals enter health institutions.

Keywords: journalist ethics, health ethics, laypeople, patients, mental illness, health coverage, reality TV

Reality television (TV) and documentaries featuring hospital patients in treatment have become a widespread genre. Such programs occur in various institutional settings, from emergency rooms to maternity departments, children's hospitals, and psychiatric departments. These formats epitomize a broader trend of personalization and intimacy in the media (Coward, 2013; Hinnant, Len-Ríos, & Young, 2013; Hornmoen, Fonn, Hyde-Clarke, & Hågvar, 2020). Indeed, they also accentuate vital ethical dilemmas of agency and privacy common to the wider field of documentaries that feature lay individuals in vulnerable situations. However, despite these programs' high audience ratings, adaptations to new platforms, and international spread, scholarly interest in TV productions occurring within health institutions has been limited (see Blaker, 2017; Hill, 2000). Addressing this gap, this study investigates the experiences of patients in a TV documentary series based on footage from mental hospital wards, asking:

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RQ1: What are the premises for agency and informed consent for hospitalized patients participating in documentary series productions?

Unlike the scarce academic interest in the TV formats set inside health institutions, many studies have focused on the wider phenomenon of so-called “therapeutic TV,” where laypeople participate in talk shows and reality TV, focusing on confession and disclosure of different types of health challenges and stigmatized conditions (e.g., Gamson, 1998; Hill, 2000; Ouellette & Hay, 2007). These formats were often critiqued concerning both the seemingly voyeuristic character of the participants and the exploitative nature of confessional TV, catering to the interests of producers rather than helping or healing the participants (Grindstaff, 1997; Shattuc, 2014; White, 1992). This type of critique has been less pronounced about the formats in focus here. Even if the programs filmed inside health wards are sometimes criticized for their exposure to patients’ privacy (Krakower, Montello, Mitchell, & Truog, 2013), they are more widely praised for their ability to enlighten the audience, contribute to the normalization of illness and hospital treatment, and acknowledge the experiences of those afflicted by disease and their calls for improved treatment (Hill, 2000; Plomin, 2013; Szasz, 2007; Wrong & Baumgart, 2013). Hence, from a journalistic perspective, the media presence in hospitals may be defended by the obligation to provide public information and to give voice to the voiceless (International Federation of Journalists [IFJ], n.d.; Society of Professional Journalists [SPJ], n.d.).

The question remains, however, which premises for agency and voice are actually offered to the patient participants in this type of TV production. Arguably, they take place within what Goffman (1968) labels “total institutions,” in the sense that the otherwise separate life spheres of the individuals (the privacy of home and rest versus public participation in work, education, and play) are collapsed into one arena, in which 24/7 routines and treatment interventions are decided by professional institutional rules (Goffman, 1968, pp. 11–15). Since Goffman, patient rights have been augmented, and medical elites are no longer surrounded by the same degree of deference (Szasz, 2007). However, even if modern health ethics sanction the integrity and autonomy of patients, hospitalization, by necessity, implies a certain surrender of control and a high degree of dependency for patients whose medical conditions require care and treatment. After all, amid an illness, it is not a real option to exit treatment and withdraw if and when a TV crew appears at your ward. This setting invites a careful consideration of whose interest is served when personal stories of illness are revealed (Costa et al., 2012), and the role played by both health and media professionals in the process. To probe the premises for consent and autonomy within this context, we investigate how patient agency—the rights and abilities for patients to stay out or to choose participation—is attended to and experienced through the different phases of TV production happening inside hospital wards: how access to the institution and recruitment of participants takes place; how participants experience the presence of a TV crew in their wards; and how participants react to their final TV portrayals. The analysis relies on a theoretical framework that discusses the intersection between health ethics and journalistic ethics about autonomy and (informed) consent, and how formal and informal agreements, obligations, and trust are negotiated between reporters and lay participants.

Analytical Framework

Patient Stories and Health Ethics

Interest in personal stories of illness, and the witnessed experience of fighting disease, has flourished both in the professional disciplines of medicine, psychotherapy, humanities, social sciences (Woods, 2011), and in popular culture and the media in the last decades (Coward, 2013; Furedi, 2004). The focus is surrounded by a discourse that emphasizes the personal and societal values of openness about personal experiences of illness (Ytreberg & Thorbjørnsrud, 2020), notably destigmatization (e.g., Corrigan et al., 2010) and the personal, positive effects of self-disclosure (e.g., Smyth, Pennebaker, & Arigo, 2012). Notably, Frank (2013) proposed that storytellers, by sharing their testimony of illnesses, can create personal meaning and repair damage caused by illness while helping the listener and enabling the storyteller and listener to unite in their shared vulnerability. However, for Frank, some phases or contexts of illness tend to preclude the storyteller's ability to take ownership of and find his or her own meaning and voice. For example, the *chaos story* lacks narrative order because immense suffering and a lack of distance from acute illness can hamper the afflicted person from verbalizing and giving meaning to the experience.

Frank's notion of what it takes to tell one's own illness story in a meaningful way reveals some pertinent dilemmas related to allowing a TV crew access to severely ill patients. When film crews enter medical wards, the fundamental health ethical principle of avoiding harm and securing confidentiality and informed consent, enshrined in the jurisdiction governing the license to provide health care (Magelssen, Førde, Lillemoen, & Pedersen, 2020), meets with practically oriented case-by-case journalistic ethics based on obligations to both the wider society and the individual.

Within medicine, the ethical principle of *patient autonomy* has become an essential value in today's health services (Magelssen et al., 2020, p. 63). Beauchamp and Childress (2013) discuss autonomy based on (1) intentionality, (2) understanding, and (3) noncontrol (i.e., neither being controlled by external sources nor by internal states depriving "self-directedness"; p. 104). Closely related to patient autonomy is the principle of *informed consent*, which includes (solid) information, competence (to consent), and voluntariness (Magelssen et al., 2020). This principle specifies that patients who are competent to make decisions must receive adequate information about the risks, benefits, and alternatives of choices. The dynamic nature of patients' wishes is recognized, and informed consent requires that consent may be withdrawn both within medical research and clinical practice until a point of no return has been reached (Krakower et al., 2013). Relatedly, rules of confidentiality are essential in protecting patients' privacy, integrity, and trust in health services. As the main rule of informed consent, patients must approve that their health information is being shared with others (Magelssen et al., 2020).

Beauchamp and Childress (2013) emphasize that autonomy, as an ethical value, must be weighed against other values (i.e., of doing good and not causing harm). They further highlight how autonomy encompasses the absence of "undue" influence within a health institution, underlining the patient's vulnerability, the dependent relationship, and the power asymmetry between the patient and health staff. Indeed, feminists and care ethicists have argued that the belief in autonomy has become too dominant within health care (cf. Delmar, 2012), criticizing the notion of independent, rational choice, and highlighting

the complexities involved in a person's autonomy. Individuals are relational, they argue, and sometimes they depend on others (cf. Mackenzie & Stoljar, 2000; Osuji, 2018).

Journalistic Ethics and Autonomy

Where health professionals' primary obligation is to patients, journalists' mandates are defined by several obligations to society. Within journalistic professionalism, there is a strong norm of independence and, thus, of journalistic autonomy (Hanitzsch & Örnebring, 2019) to secure access to and delivery of vital information to the public. Furthermore, freedom of information is a recognized right reflected in the rules of the General Data Protection Regulation (GDPR), which largely exempts journalists from the strict provisions researchers and health-care providers must adhere to (Ethical Journalism Network [EJN], n.d.). Notably, in journalism, there are also ethical standards for minimizing harm and showing consideration to vulnerable persons (EJN, n.d.; IFJ, n.d.; SPJ, n.d.). An ethics of care and compassion for those who may be adversely affected by news coverage implies a particular sensitivity toward people who suffer from trauma or illness or otherwise have conditions that might prevent them from understanding the full implications of appearing in the media. Unlike the formal codes of health ethics, these are overall norms defined by practical and informal situational ethics, largely leaving to the individual reporter or news desk a case-by-case judgment about how to balance the need to protect vulnerable individuals with society's need to know (Nash, 2011).

Essentially, the tasks of journalists and the media industry are not defined solely by the imperative to oblige professional ethical codes; rather, it is also the media's job to reach and engage a mass audience by involving dramaturgical criteria and captivating visuals (Palmer, 2018). The possible conflict between the ethics of care, the mandate to provide vital information to the public, and the instrumental interest of making a good story represents a recurrent dilemma for journalism in general, but it becomes extra potent within reality and documentary programs that involve particularly vulnerable individuals.

To be a good reporter, inducing trust and getting people to open up require fine-tuned social skills and a display of empathy and concerned interest. This behavior is indeed recommended as the most decent and ethical way to approach people who are amid extraordinary crisis and trauma (Healey, 2019). Concurrently, as Palmer (2018) argued, to be a good listener and make people feel better is not in itself an end in encounters between reporter and source; by necessity, these approaches are also a means to get a good story out there to the audience. This dilemma is familiar to the wider documentary tradition. Several documentary scholars and producers have pointed to a paradoxical relationship between the formal autonomy and copyrights of producers on the one hand and a more informal moral practice of care and protection on the other (Nichols, 2016; Pryluck, 1976; Winston, 2000). Through a release form, filmmakers must secure the formal consent of the individuals they want to put on film. These standard forms, however, do not detail rights to withdraw or comprehensive information about the implications for participants; rather, they bolster the juridical right of the production team to fully control the materials, including the use and reuse of footwork and rushes. Hence, as opposed to the principles of informed consent in research and clinical health practice, the templates of the film and TV industry are more about giving up control than keeping it for those signing (Nichols, 2016). This conclusion has led some practitioners to adopt the principles of coproduction, which provide lay participants with more influence

on the framing of their stories. Other practitioners allow extra-vulnerable participants more comprehensive information and opportunities to suggest changes to how they are portrayed. As these practices tend to remain informal and not part of binding juridical contracts (Nash, 2011), it is vital to explore the functions of both formal agreements and informal understandings to build trust, obtain access, and narrate patient life in an institutional setting on TV.

Case and Methodology

The Case

Five Days Inside (NRK, 2015–2020²) is a documentary series that features a reporter moving into an institution for five consecutive days. The Norwegian, original version includes various in-house health wards and psychiatric and acute care hospitals. The stated aim of the production is to give a glimpse into life behind the closed doors of the institution: the people residing there and the people working there. Each episode of *Five Days Inside* starts with the reporter packing her bag in the early morning and asking herself what she will encounter in the institution, where she will live continuously for five days. Seemingly spontaneously, the reporter explores her new surroundings step by step, from being welcomed and shown where to sleep by the head of the department to greeting the staff and, most notably, the patients residing there. Handheld moving cameras closely follow the reporter, and their role is to represent a curious but rather ignorant general audience (Kasnes, 2017). When the camera crew has left for the day, the reporter stays behind to film life and encounters the institution during the night with her own small camera.

Each episode lasted 59 minutes and focused on a small group of residents in the institution. The documentary was developed by the Norwegian public broadcaster NRK, and licenses were sold to Holland, Belgium, and Poland—countries where the program has also been produced. As an NRK production, the documentary is committed to following the journalistic guidelines and ethical standards of the public broadcaster.

Viewership ratings in Norway were high, and the program has won several prizes and awards. (The program won the European Broadcasting Union [EBU] Creative Forum's third prize for best TV format, a prize for best TV programs in Holland, and was nominated for Gullruten's "best documentary series" in Norway. Furthermore, in both Holland and Norway, the reporter has won best-presenter prizes.) Adding to airing on TV, all episodes are available on the NRK website at the time of writing.

Methods

For this study, 23 people involved in the production of three *Five Days Inside* (NRK, 2015–2020) episodes focusing on mental health institutions were interviewed. Of these, 12 were in-patients at the time of filming, and their experiences were the main focus here. Notably, some of our informants (who were hospitalized at the time of filming) chose *not* to be filmed but were nevertheless exposed to the initial request and later the presence of the TV crew in their ward. The semistructured interview guide focused on

² Producers and editors are not listed here for confidentiality purposes.

retrospective reflections on motivation for and circumstances surrounding (non)participation, experiences with filming, and seeing oneself on screen. To ensure anonymity, we neither name the institutions nor draw distinctions between them. Also, we did not specify which institution each informant was admitted to or the informant's diagnosis. To further secure anonymity, gender was altered for some informants. Data was stored and processed according to strict research ethics and regulations for sensitive data. All interviews were recorded, transcribed, and coded using data analysis software (NVivo and HyperResearch). The coding was conducted by the two researchers according to the thematic focus of the interview guide and was further recoded into themes emerging from the material.

Seven interviews were also conducted with professional health staff (including the leaders) at the filmed health institutions. Finally, four central actors of the production team, referred to as Program Makers 1–4, were interviewed. These interviews were coded using data analysis software and provided context to the experiences of the patients. Communication was established and maintained through SMS, phone calls, e-mails, and Facebook Messenger. Except for two shorter interviews with health staff, each interview lasted between one and two hours, with an average duration of 1 hour and 10 minutes. The study was approved by the Norwegian Center for Research Data (NSD).

Analysis

Preparticipation: Information, Motivation, and Trust

To the audience, the reporter's visits to the hospital wards on *Five Days Inside* (NRK, 2015–2020) appear immediate and impulsive. In reality, the reporter and her team's entries proceeded through a long process of dialogue and negotiations. The first step for the production team was to obtain access from the gatekeepers (i.e., the executive level of the three health institutions). Once given this approval, the health staff (department head) informed the patients that a TV crew would arrive and that they aimed to recruit patient volunteers who would actively participate in the production. Two researchers from the production would then visit, typically during morning meetings with patients and staff, and present the idea behind the program, followed by talks with selected patients who pondered whether or not they would like to take part. It transpired that (1) the patients did not have a say in the decision to allow the presence of a TV crew in their wards and that (2) their final decisions to be filmed and to participate as identifiable characters in the production was based on consent between them and the TV team.

In the initial dialogue with the hospitals about getting access, the TV crew would emphasize the value of "openness" and that filming life in psychiatric institutions would present an opportunity to fight stigma, enlighten the public, and provide a voice for those seldom heard in public: in-house patients. Indeed, the production team emphasized the right to free speech of this marginalized group. These arguments ring through in interviews with the ward directors when explaining why they allowed the TV crew in and, notably, it also runs through in the information ward directors gave to their patients and subsequently in the information the TV crew provided directly to the patients, condensed in this quote from an employee at the film crew:

We usually just say hello, we are working on this program (. . .) and we have talked to the management about it, and they also think it is a good idea, if you think so. And then something about the purpose of the program, that there are many notions out there about what life is like in such a ward, and perhaps some prejudices and delusions, so now we want to show how it really is for better or worse. And that openness is sort of our mission. (Program Maker 1)

Heads of departments were typically motivated by the chance to educate the public and enable people to seek help. One of the therapists also encouraged patients to participate in *Five Days Inside* (NRK, 2015–2020) as a form of therapy to relieve feelings of shame:

We presented it as an opportunity for them to share their experiences with others in similar situations, and that they, by stepping forward, could render hospitalization less scary, normalize it in a way, and make it easier for others to seek help (. . .). Disclosure kills shame; it gives immediate results. That insight made it justifiable for me to expose the patients to yet another strain. (Health Professional 2)

These are perspectives mirrored by many of the patient participants, who expressed how they were motivated by the opportunity to help others and to destigmatize mental illness, as this informant's quote illustrates: "To show that we are not dangerous. I was very passionate about that" (Patient 5). Further, several patients believed that participation could help in their healing process: "I thought it might remove some of the shame, that OK, now it is not such a big deal, now that everybody knows, it is okay. No need to cover up and hide anymore" (Patient 2). Another participant explained how she discussed it with the staff: "They thought it might be inspiring to me. And for others too" (Patient 11).

Several participants felt that the program makers and professional staff indeed hoped that they would participate, and some recalled how staff members would inform them that there *had to be* a few willing to participate for the production to go ahead. Also, the directors of the wards conveyed that, at this stage, they all felt enthusiastic about the filming. That noted, most participants expressed that they did not feel direct pressure to participate: "I felt I was involved in the process; I was not run over in any way" (Patient 1). The premises for their decisions, however, seemed rather heavily framed by the department leaders responsible for the patients' treatment, even if the enthusiasm was not shared by all therapists at the wards. Tellingly, one patient perceived that the information from both the staff at their wards and the program makers was overly positive:

The department leader was optimistic (. . .), and they (the researchers) talked about how "Yes, you can make a big difference by participating, it will be important, and maybe you will be contacted by the press later and so on. You don't have to say yes, but it is nice to be a voice and maybe show what it is like to be hospitalized here, show a different side to it (. . .). I was very off and on, but eventually I became like, "Yeah, maybe it will be nice, then." (Patient 4)

Some patients were immediately positive about participating. For others, the decision was subject to substantial considerations and doubt. A vital strategy for the production team was to build trust so that the participants would feel safe enough to disclose in their interactions with the TV crew and the camera. To win patients' confidence, presence, and personal contact over time was key. A research team of two to three people is normally present at the wards for several weeks before filming, taking part in daily routines, eating with, and talking to the patients. To many informants, both patients and staff, the researchers were gradually perceived as part of the institutional environment—such that one informant described them as “sort of becoming one of the patients” (Patient 7). The same researchers were also present during filming when they worked as editors, guiding the “unknowing” reporter toward certain subjects and topics that they knew were worth recording. Without exception, the informants genuinely *liked* the research team: “They were such sweet and wonderful people” (Patient 9). This perception was largely shared by the leaders and staff at the institutions.

Although the reporter herself was not part of this familiarization process, the aim was to establish a space of trust and safety, preparing for her and the camera crew. The long research period alongside the establishment of trust among leaders, staff, and patients, is recognized by the program makers as a precondition for the production. The instrumental aspect (i.e., the researchers' interest in making a good and popular program) seemed toned down compared with the patients' feeling of moral obligation to accept a request for information from good people about a worthy cause:

They were very nice to talk to. It was easy to open up to them (. . .) when they came with the camera, it did not seem like it was aimed only at TV: they seemed interested in hearing what I had to bring forth. (Patient 11)

Formal Agreements vs. Informal Rights

An essential aspect of creating a safe atmosphere was the program makers' assurance that the participants would ultimately control the presentations of their stories. They were encouraged to be fully transparent in the filming phase and were assured by the TV crew that they could always edit the content after filming or even withdraw. However, although the opportunity to edit and withdraw was important for most informants, it was unclear for them whether or not this right was enshrined in the signed agreement between them and the TV crew:

Patient 1: And I could withdraw too, they said: that I could withdraw.

I: Was that stated in your contract or?

Patient 1: Yes, yes. I think so. I don't remember exactly what was in the contract, but I think I could have withdrawn anyway, even until the day before the program was to be broadcast. (Patient 1)

Most of the participants believed that the right to edit and withdraw was part of their formal contract of consent, while the agreement included such formal rights only for patients in one of the institutions. Basically, the template used reflects a standard juridical contract of ownership and secures the broadcaster all rights to the footage material, with no time limit, and replication on all platforms, including social media

(Shufeldt & Gale, 2007). From there, the consent agreements in use varied in length from many pages to shorter or ultra-short versions; that is, only oral consent was recorded on camera. In one institution mentioned, this formal agreement was modified, favoring participants' right to withdraw at any stage until five days after watching a fully edited version of the episode. This modification was because of the involvement of juridical experts in this particular institution, negotiated as a premise for access. Notably, this right to withdrawal did not encompass the time after publication when all rights to the (re)use of the material rest with the broadcaster.

Overall, more than through formal rights, the participants' agency and right to withdrawal were based on informal agreements. The fact that the TV crew nevertheless relied on standard formal contracts reveals the ambiguous relationship between an instrumental need for productional predictability versus care for and protection of the participants:

A contract is more than a legal document (. . .). It also makes people aware that now you are on TV, it commits in one way or another. You should have thought through why you want to participate and what you are participating in. But nothing is written in stone, so if someone wants to withdraw, we don't say, "Now that you have talked to us, it *must* be on TV." (Program Maker 2)

Notably, a couple of our informants from *Five Days Inside* (NRK, 2015–2020) had trouble remembering much about their consent to participate and the circumstances surrounding it. Some pointed to their state of illness, distress, or the impact of medication at the time, while others could not explain why they did not remember more. One person had particularly little memory of meeting the film crew, let alone signing any sort of consent form: "The thing is, I don't really remember the camera (. . .). No, I don't remember, but I have probably signed because I think one must sign to do it. I don't know" (Patient 3). At the time, she could not decode what was going on around her: "I was so tired, and I was sedated too, so I didn't register half of what she said" (Patient 3).

Indicating the central role of felt moral obligation and trustful encounters rather than negotiations between potentially conflicting interests, only two patients—those among the oldest of the informants and those not afflicted by the most severe diagnoses or in acute stages of illness—set down their own personal conditions for agreeing before the filming phase.

Intervention: When the Camera Is Running

When the TV reporter finally enters the institution, followed by a camera person, a new phase in the interaction between the production team, patients, and staff begins. As for the researchers, the key aim of the reporter is to create empathetic and trustful encounters. Several of the informants, both patients and staff, highlighted that they found the reporter very sympathetic, warm, and easy to talk to. Some became particularly attached, and one admitted to being starstruck by meeting the famous reporter. Another participant conveyed how she first was scared to disclose before the camera, but the presence of the reporter made it easier: "She is such a good person to talk to. She is so calm, and when she asks, she asks in such a pleasant way. And one sees that she really cares" (Patient 9). Others recalled how the presence of the

camera crew was uncomfortable in the beginning but that they got used to it and ceased noticing it, even when sharing personal and painful experiences with the reporter. One person even felt that the presence of the camera helped him overcome mental challenges. Urged to talk in front of a group for therapeutic purposes, he recalled:

I dreaded it enormously in advance, but when I entered, and there was this enormous camera in front of me, pointing at me, and yes, it is a bit strange, but I thought something like, now, this will be on TV and stuff, now it's all about finding the fighter and the winner instinct, and I am going to nail this. (Patient 2)

In some situations, the participants doubted whether they should let the film crew be present (e.g., in treatment sessions or in meetings with close family). Some refused, including one under the influence of his therapist: "I think I said no once to a treatment interview. It might have been my psychologist who was most eager to decline" (Patient 10). In general, the middle-aged informants and those with the least pervasive or acute diagnoses expressed the highest degree of self-interest about how and when to disclose to the TV crew: "I didn't pay any attention to them if I was in a bad mood, I couldn't bear talking to them, and they respected that" (Patient 9). Others allowed the TV crew to join a treatment setting, reassuring themselves that they could change their minds at a later point: "In the back of my head, I thought this can be edited out" (Patient 7).

For some participants of *Five Days Inside*, however, the mere presence of a reporter and cameras in their ward induced severe distress. One patient described a feeling of creating a false, overly positive image, which concealed how difficult things actually were: "Yes, I became more stressed. Because then I also had to try to pull myself together (. . .), like, I had to cope with so many things; I felt like it increased the pressure" (Patient 11). Importantly, some patients found it difficult to define their borders for disclosure, and one young informant, who ended up withdrawing from the episode, explained that she did not dare to say no to the film team when they asked if her family would take part: "They really wanted to film parents, and I didn't dare to say no because no one else wanted to include their parents. So, [my parent] participated, and it was actually really uncomfortable" (Patient 4). For others, the instrumental element of the encounter became evident when the TV crew entered their wards. For one of the patients, this perceived dominance of TV logic was unexpected, leaving a feeling of betrayal:

I think no one could imagine that it would be like that and that many had a naive belief that this was about public enlightenment (. . .) but then I realized very quickly that it was about [the reporter]. And about TV: good TV. (Patient 8)

To these informants, when the reporter and cameras arrived, their wards were turned upside down. A feeling of being taken by surprise was also expressed by one head of department, as she gradually came to perceive the presence of the TV crew as a revelation of the true dramaturgical nature of making good TV. "It was an incredibly exhausting week for everyone" (Health Professional 1) she recalled, particularly emphasizing the reporter's practice of contacting patients in their private rooms and initiating talks late at night:

She did not seem to understand that going in at night with such vulnerable patients, who might suffer from self-harm and suicidal thoughts, that opening something up just before bedtime when the day has been exhausting . . . she did not understand why that is a very bad idea: it was completely naive of me to take that understanding for granted. (Health Professional 1)

A few patient informants were critical about what they saw as the reporter's lack of understanding about the complexity of the patients' mental diagnoses and their degrees of vulnerability. They found that she used her seeming naivety strategically and that she asked highly insensitive questions. They also reacted to what they saw as the reporter's attempt to make friends, creating close attachments with people in great need of attention and care, which might be used for instrumental purposes:

The reporter was really sweet, and she's very good with people, for sure, and I experienced that too, that she was very warm, and by being that, she got information that she would not get otherwise, by becoming a bit friendly with us, behind the camera, giving hugs, etc., and that is a way to build trust. (Patient 4)

It is also worth noting the experience of reduced therapy output among some of the patients who did not appear on TV but who were exposed to the presence of the camera crew. One informant—although basically supporting the documentary project—perceived the attention of the staff as primarily directed toward those who had agreed to be filmed: "It was very much focused on the two–three persons who had agreed to be filmed (. . .). I felt a bit like hmm, could almost just stay at home this week" (Patient 6).

A sense of insecurity and a lack of privacy arose in some of the informants during this week. Some patients were in forced detention; others were, for all practical purposes, confined within the walls of the hospital. Notably, not all patients wished to be filmed. However, one patient with a diagnosis that allowed her to leave the hospital and come and go at will found it relatively unproblematic to stay outside the camera lens, while others were in such a state that the mere presence of the cameras provoked deep anxiety: "It was very difficult: some didn't dare to enter the hallway because they heard she was there. (. . .) Five days is quite long when you just live there and have it pretty shit" (Patient 8). For this informant, what contributed specifically to a feeling of invasion was that the film crew was allowed to use a drone to film the hospitals from the outside:

I was standing in my room, with these big windows, and then all of a sudden there comes a drone, and it was, like, trespassing, invading, and I don't know how much they saw, and they haven't used that footage—me standing there with just my bra—because I was going to change, but it was so, you got the feeling that from all sides you are seen and exposed and attacked, almost (. . .). Then you really felt that okay, now we are on TV, now it is the TV rules that matter. (Patient 8)

The degree of anxiety triggered among some of the patients did not seem to be realized by either the health staff or the TV crew. For example, one program maker pointed to how the patients who did not wish to be filmed were placed at their own table during meals and were therefore well protected:

I think they just felt safe that we didn't film them. I don't think they went around being afraid of that. We were very clear on that. And the management looks through the program afterwards, so it is absolutely taken care of: that the anonymization is complete. (Program Maker 1)

Feedback and Control Over Exposure

It was a vital informal premise for the filming that participants would watch a raw cut of the episode before publication and have a say about things they might want to edit. With this opportunity to give feedback, many participants experienced a relatively high degree of perceived control over the final product. However, not many recalled that they expressed any objections to how they were represented. In general, those who did were among the oldest, not in an acute stage of illness, and not stricken by the most severe diagnoses. One of the cohorts emphasized how his objections were listened to when he reacted to a depiction of him as a bit of a clown: "Some things were just nonsensical to me. The others said it was fun, but I said, no, I don't want to appear like that. And that was all right. It was removed; there was no discussion about it" (Patient 1).

In general, seeing oneself on screen was emotional for most informants; for some, it was painful and provoked anxiety. Many expressed it as vital to watch the episode alone, often several times, at home. They did not manage to process the episode while they were gathered to watch it: "I didn't manage to watch, because then the anxiety was so high. (. . .) So, we got it on file and watched it in peace and harmony at home, sort of. And then I could process everything" (Patient 9).

Vitality, though, a few were (still) very sick at the time of the preview and did not remember much of it. One participant explained how she hardly managed to get herself to meet up at NRK, let alone process what she saw and certainly not object to what she perceived as a pitiful depiction of herself: "I could hardly speak because I was so anxious (. . .). I somehow couldn't say what I really wanted" (Patient 3). Another participant explained how she hid her eyes when she watched the preview because it was too difficult seeing herself. She had no comments about the edited version and had never watched the entire episode. Finally, the hospitalized informants who *disagreed* with being filmed by *Five Days Inside* (NRK, 2015–2020) were not invited to watch the episode, yet some of them felt anxious that they would be recognized. One, who chose to exit, pointed at the fact that, for those who knew her, she was recognizable in the published episode. Her face and clothes were blurred but not her characteristic slippers.

Self-Directedness and Uncontrol: Difficulties with Exiting Production

Most participants, even some of the most anxiety-ridden, never considered withdrawing from the production: "Even though I was sitting there [watching the raw cut] packed with anxiety, I thought deep down that it is natural, this, to sit and dread all that" (Patient 2). A high degree of ambivalence was nevertheless experienced by many, such as Patient 7: "Have I done the right thing, have I not done the right thing, should I withdraw? It is not possible" (Patient 7).

Some felt uncomfortable with the filming or how they were presented that they considered withdrawing, either before the filming started or sometime during the process before the program was aired on TV. Reaching that decision was not easy. One participant felt very distressed about being part of the program: "I had a lot of thoughts about it, and I was actually, I thought, am I to call her and tell her she cannot have me join?" (Patient 3). She never did mainly because she did not want to miss the opportunity to help other people: "So I didn't really want to, but at the same time I had all those thoughts about helping others. And when such things come up, then that side always wins—not really what I want for myself" (Patient 3).

Another informant decided to withdraw after realizing that her perspective on her illness would not appear in the TV program and that she would be presented in a way she could not identify with. Before she finally managed to withdraw, she discussed her dilemma with one of the nurses, a crucial step in her decision-making process: "It was vital for me to have someone to talk to and support me because I had signed a contract and withdrawing gave me such a bad conscience. I recalled it as a terrible torment" (Patient 8).

The signed contract also became essential for another participant who decided to withdraw. Although she was enrolled in one institution with a formal clause about the right to withdrawal, she felt like the head of her ward had tried to prevent her from withdrawing, in fear that the whole program would have to be canceled: "It appeared as if it was sort of little embarrassing for them" (Patient 4). However, when this participant finally talked to the TV production team, she did not encounter any barriers from their side and was edited out.

Some of the patients filmed in *Five Days Inside* (NRK, 2015–2020) were in a state of acute illness and chaos (Frank, 2013), where they had relinquished much control to hospital staff at the time the film crew visited their institutions. For the informant who struggled with the decision and was finally able to withdraw, it was vital that her condition had improved and that she gradually felt stronger. She explained how, at this stage, she saw many things differently from when the TV crew first entered her ward: "Time had passed (. . .) and I gradually became more aware of what I wanted and not, and I guessed I dared to say no to things, feeling safer with the staff" (Patient 4).

Doing Good or Doing Harm: Patient Reflections in Retrospect

Looking back, many informants were proud of their part in *Five Days Inside* (NRK, 2015–2020): "I've taken part in something important (. . .) so I can stand for it anyway" (Patient 1). Others felt that their participation had contributed to their healing: "Openness has led to me having a slightly different relationship to, and a slightly different view of, the disease. So that in a way I can use it for something, rather than just having it as a burden" (Patient 5). A perception of having contributed to stigma reduction in society is a central theme in the interviews, and for some, media participation helped to reduce their self-stigma (Corrigan et al., 2010), such as Patient 2: "I don't have to keep my mask on and say that everything is going well, and that has been a relief" (Patient 2). Another participant nuances the effect of media disclosure and generally learns to be more open:

In the long run, I think that maybe not the fact that I have appeared in the media has made me healthier, but I have managed to be more open. And that is important: that you can talk openly and honestly about it. (Patient 7)

For some informants, however, participating in the program had consequences that they did not foresee—among them, the deterioration of their illnesses. Two weeks after the program had aired, one of the participants was hospitalized: “I simply felt mentally ill from it” (Patient 3). She looked back at the program with deep ambivalence and felt more scared in social settings than before:

I am very grateful that I got the chance to help others, but concurrently, it has affected me much. The fact that I actually got more anxiety when I’m at the store and places like that because people recognized me. (Patient 3)

This informant found it a burden that the program remained available online and that it was shown for educational purposes in schools and colleges. Patient 7 also expressed ambivalent feelings about whether she would participate in this type of program again: “I’m glad I participated, but sometimes I think, shit, perhaps I shouldn’t have done it. So, it’s a bit of both.” Another informant, who did not participate but who was exposed to the presence of the film crew, was critical about her institution granting access to the TV crew in the first place. The feeling of privacy invasion and reduced therapeutic output by in-patients *not* appearing on the camera also reflected negative experiences not accounted for by health staff or production crews.

Notably, those who had refused to participate felt they had made the right choice, either because they disliked how mental illness was presented in the program or because they simply did not want to focus too much on their illnesses: “I don’t want to go around every day thinking that I have [a mental illness], and I feel that if I participate in such a production, then there will be a lot of focus on it” (Patient 6).

Discussion

Analyzing participation in *Five Days Inside* (NRK, 2015–2020) through the lens of the health ethical values of *autonomy*, *doing good*, and *not causing harm* reveals some of the dilemmas that may arise in media productions when health and journalism ethics and practice meet. First, ensuring that patients possess the necessary *understanding* to give informed consent to participate in media production is a complex task but is essential for autonomy (Magelssen et al., 2020). In retrospect, some of the patients and some of the health staff expressed that they had not grasped what this TV production would actually entail when they gave their consent. For them, the instrumentality in the journalistic encounter (Palmer, 2018) was overshadowed by references to the values of providing public information, being open, and helping others, while considerations of potential negative consequences for the wards or for individual patients were downplayed. Without real-time observational studies, we cannot know exactly which information was provided at each step in the process, but participating in *Five Days Inside* appears to have been presented to patients first as an opportunity to help others and potentially themselves. It follows that the possible conflict between “good TV” and giving a representative picture of a day in a hospital ward or depicting the complexities of mental diagnoses may not have been made explicit. This also seems to be the case for how the program idea was presented to the health professionals and gatekeepers who, on their

part, did not seem to consider in depth how the presence of a TV team would actually interfere in daily routines, routines that, for many patients in themselves, were part of their therapy, and challenging enough to attend to without the presence of a TV team.

Considering the power asymmetry and relationship of dependence between patient and health staff (Beauchamp & Childress, 2013; Delmar, 2012) and even just the felt moral obligation to say yes to a request from journalists (Palmer, 2018), this challenges the perception of independent, rational patient choices in this case. The patients' decisions to participate or withdraw were framed in important ways by health staff and program makers; it was not the patients' own initiative to disclose their mental illness on TV. The TV crew was granted access by the health administration and staff before the patients were asked. Further, while several patient informants had difficulties remembering much from that period at all, one patient was in such a mental state that she did not even realize she was being filmed when it happened, a clear example of a situation in which informed consent is not possible.

Finally, participants' own accounts of their feelings of control vary. Some, particularly the oldest and those beyond an acute, life-threatening state, felt able to control both the extent of self-disclosure to the cameras and the presentation of their illness stories in the editing process. Several of these patients also experienced their TV participation as beneficial, helping their healing and making them feel proud of themselves. Others, particularly those who recount having been in a state of acute and severe illness (Frank, 2013), felt various forms of lack of agency, from difficulties with regulating their own borders of openness, invasions of privacy, increased anxiety, and loss of control over their own stories after publication—all this points toward reduced autonomy and even a certain harm.

Considering the effects on some patients, one may ask if the necessary premises for informed consent that are vital for the realization of true patient autonomy, and the principle of avoiding harm *and* the ability to have one's own voice recognized, were fulfilled in this case. An increased sensitivity toward how relations of dependency affect autonomy (e.g., Delmar, 2012; Mackenzie & Stoljar, 2000), and a better understanding of the media logics and implications of the TV format might have yielded more cautiousness. Notably, neither the health staff nor the production crew seemed to have realized the degree of anxiety and discomfort for some of the patients involved. If these patients had been able to mark their borders with more strength, they might have been better shielded from the TV crew. However, when patients are in a mode of chaos and acute illness, their duty to protect and care lies first with the health institution and second with media professionals who ask for permission to film. Our hope is that this study will increase the sensitivity of both health staff and TV production crews in the future and provide an increased understanding of when media exposure to illness may be beneficial or ultimately cause harm.

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