

## CHAPTER 10

# Patient Narratives: Health Journalists' Reflections, Dilemmas and Criticism of a Compelling Journalistic Tool

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*Media stories of health and illness are omnipresent. The plethora of available health stories not only inform and educate, they invite us to engage, identify and act, thereby priming basic feelings of fear, hope, identification and a sense of justice. In recent decades, the patient narrative based on the personal experience of individual patients, has come to represent a recognizable genre across hybrid media and popular culture. Patient narratives are rhetorically powerful, but the patients themselves may be in a vulnerable state and in need of particular carefulness. For the 12 health reporters and editors interviewed for this chapter, exposing individual patient stories raises different ethical challenges than using professional sources, potentially altering the balance between professional empathy, involvement and distance. The chapter illuminates the professional dilemmas, ethical considerations and critical reflections that the health reporters experience in their use of personal patient stories as cases and journalistic tools.*

**Keywords:** health journalism, narratives, professional ethics, human interest

## Introduction

The aged celebrity who gives another tell-all-interview about his ailing health. The four-year-old who suffers from a rare syndrome and can die tomorrow.

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The community fearing for their lives if the local hospital is closed down. The healed patient who found a miracle cure. The chronically ill women fighting for a medical diagnosis. The three-year-old cancer victim, and the twin brother he left behind.

We meet intimate stories of suffering, strength and support across networked media, popular culture and in the news media (Frank, 2013). Today, personal stories of illness and health thrive on networked and social media platforms, where the unedited, lay-expert voice of the patient recognizes and makes visible perspectives that have previously been private, peripheral or invisible (Orgad, 2005). Social media are designed to encourage emotional expression and engagement (Hermida, 2014; Wahl-Jorgensen, 2016), and in hybridized media landscapes emotional approaches are crucial to attract and engage much-needed news audiences (Beckett & Deuze, 2016). These patient narratives engage, touch and provoke us. They offer us insight, identification and empathy, and can provide support, community and empowerment for those involved (see among others, Hansson and Wihlborg (2015)).

At the same time the mediation of people's personal struggles also potentially simplify, emotionalize, (self-)expose and push vulnerable people into public scrutiny (Coward, 2013). For media organizations, patient narratives thus represent both a potential and a professional responsibility. The use of human exemplars as a narrative tool in health and science journalism has been common, yet contested (Amend & Secko, 2012; Hinnant & Len-Rios, 2009; Hinnant, Len-Rios & Oh, 2012; Karpf, 1988; Morlandstø, 2006; Mullan et al., 2006; Seale, 2002; Tanner, Friedman & Zheng, 2015; Viswanath et al. 2008). For health journalists in mainstream news organizations, working with and on patients' personal stories can challenge ethical codes. Patient narratives are powerful, but the patients themselves may be vulnerable and in need of particular carefulness. For health journalists, employing patient narratives challenges the professional balance between empathy (to listen and understand), engagement (to get involved in the story) and distance (to keep a critical overview) (Glück, 2016; Morlandstø, 2006).

To contribute new insights into how journalists and editors meet these challenges the present chapter asks: *How do health journalists and editors reflect on the editorial practices and ethical dilemmas they face when patient stories are used as narrative tools and sources?* Based on in-depth interviews with 12 Norwegian health reporters and editors, I aim to contribute to health

journalism literature in particular, and more generally, to the reinvigorated academic discussions on emotions, vulnerability and ordinary people in professional quality journalism. Working with vulnerable sources is resource-demanding; it tests regular professional boundaries and ethical principles, yet offers unique insights and underreported perspectives (Larssen, 2009). Still, how journalists meet vulnerable sources has been largely under-researched in extant material on source-reporter relations, which has largely emphasized media-elite relations (Manning, 2001). To fill this research gap and discuss ethical awareness and dilemmas are all the more urgent today, when more individuals going through trauma and illness share their inner thoughts, feelings and experiences across and between media platforms; the mainstream media's monopoly as news producers has been fundamentally challenged; and journalists must produce more news for more platforms in less time than before (Beckett & Deuze, 2016; Waisbord, 2013).

## **Analytical framework: Emotionalizing mediated health debates?**

The news media possess the power to let people speak or to silence them, to give groups a voice or leave them voiceless (Couldry, 2010). Pioneering systematizations of media access have illuminated how official, authoritative, professional sources, enjoy crucial advantages in the competition for news access (see Manning (2001) for an informative overview). In health journalism, numerous studies of sourcing practices identify the dominant sources to be scientists, medical experts and government officials (Amend & Secko, 2012; Forsyth et al. 2012; Hodgetts, Chamberlain, Scammell, Karapu & Nikora, 2007; Hornmoen, 2010; Morlandstø, 2006; Viswanath et al., 2008). The health sector is characterized by rapid progress and the expansion of medical science, described as the medicalization of society (Clarke, Mamo, Fosket, Fishman & Shim, 2010; Conrad, 2007; Nettleton, 2013). As contemporary health and medical science is increasingly specialized and technical, health reporters are largely dependent on medical expertise (Tanner et al., 2015; Viswanath et al., 2008) and often perceive themselves as translators and interpreters of medical information (Forsyth et al., 2012; Hinnant, Jenkins & Subramanian, 2016). Over the last 50 years, the relative dominance within the elite segment shifted from health authorities and individual physicians to expert sources in medical

research and, more recently, the pharmaceutical sector (Hallin, Brandt & Briggs, 2013; Karpf, 1988). Medical experts are used to clarify, shape and illustrate stories, and to lend credibility to the story and reporter (Amend & Secko, 2012, p. 260). Scientists in particular are perceived as trustworthy sources, secured by credible processes (peer review), institutions (universities) and experts (independent academic researchers) (Forsyth et al., 2012). Reflecting this authoritative position, journalists often foreground biomedical stories and templates as a core issue in the coverage (Hallin et al., 2013; Hodgetts et al., 2007; McCauley, Blake, Meissner & Viswanath, 2013), whereas the costs and failures of medical interventions are largely ignored (Schwitzer, 2013).

The structural factors that give advantages to elite sources do *not* give them *carte blanche* access to the news, however. Elites can rarely control (promote and restrict) information flow at their own convenience, and are confronted by external competition, intra-elite conflicts and negotiations with journalists (Manning, 2001, pp. 148–49). In the health sector, traditional medical authority has increasingly come under pressure, as medical expert-patient relations have changed profoundly over the last 50 years (Frank, 2013; Karpf, 1988; Nettleton, 2013; Wright, Sparks & O’Hair, 2013). The traditionally strong professional authority of medical doctors has been continually challenged in societies where the right of citizens to be informed and to criticize established powers has been gradually established (Schudson, 2015); ordinary people take greater responsibility for their health (Wright et al., 2013); and expectations and claims for treatment are higher (Nettleton, 2013). Particularly, consumer and patient rights groups have become comparatively more vocal (Nettleton, 2013). The strong lay perspective challenging traditional medical models corresponds with the emergence of the women’s liberation movement (the personal is political) (Karpf, 1988, p. 59). Patients, their families and organizations are regular voices in health news, and became a stronger influence from the 1970-80s onwards (Hallin et al., 2013; Karpf, 1988), although they have rarely represented a dominant source group. Also some patient groups are more present than others (Morlandstø, 2006). In a recent survey among Norwegian health journalists, however, patients constitute the most used sources according to journalists (Aarebrot, 2015), serving as a point of departure for this study.

Related to this, a vital discussion in studies of health journalism concerns the narration of health news - how to balance *clarity* (making science and

medical developments accessible to the broader public) and *credibility* (without being inaccurate, sensationalist or emotional) (Amend & Secko, 2012; Hinnant & Len-Rios, 2009; Hinnant et al., 2012). In short, how to make medical and health information more accessible by using human elements,<sup>1</sup> photos or illustrations, info graphics, conversational tone and metaphors, whilst avoiding medical terminology and simplifying complex technical information (see Hinnant et al. (2012) for comprehensive discussion) is the problem. For journalists and various stakeholders in the health sector, the personal narrative represents a tool to make socially important issues more interesting for modern audiences through personalization, storytelling, case histories and model histories (Kantola, 2012). It is also appealing in that it helps readers identify with the story, reduce stigma (for certain conditions or illnesses), ground learning and make health information more accessible, and in this way affects the public (Hinnant & Len-Rios, 2009, p. 104). Moreover, these narratives represent the idealized little-person-against-the-state perspective in professional journalism (Karpf, 1988).

In their study of exemplar use in health journalism, Hinnant et al. (2013) find that journalists use exemplars first and foremost to educate and connect (humanize, identify and diminish the abstraction), as a journalistic tool to grab the public's attention (an anecdotal hook). Health journalists recruit cases from medical experts, clinical trials, or among their news audience, something that raises concerns over strategic use of exemplars to promote other interests (Hinnant et al., 2013, p. 550). Further, there appears to be a growing gap between the abstract, complex and technical discourses of medical and health care experts and the feelings, challenges and claims expressed in personal health narratives. Health journalists are recurrently under criticism from the medical community for oversimplifying medical information, as journalistic formats are perceived as undermining scientific requirements for credibility (methodology, rigor, precision and validity) (Hinnant et al., 2012). More specifically, the personal narrative has been criticized for emotionalizing and simplifying mediated health debates at the cost of scientific reason (see Hinnant et al. (2013) for in-depth discussion).

Whereas one line of research primarily analyzes exemplars as journalistic tools to make health news more accessible, a critical tradition has analyzed how

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<sup>1</sup> Also called human exemplar, human interest, individual story, case or personal narrative.

patient narratives and human exemplars are key ingredients in recurrent standardized health news narratives: a traditional conflict between a ruthless system (health authorities) and those who represent victims/patients (lawyers or medical doctors) (Seale, 2002). By foregrounding individual struggle and confronting responsible authorities, the news media meet their professional ideal of being a critical advocate for vulnerable groups in society. The media's right to access information, investigate powerful actors, and reveal failures and malpractices is widely acclaimed (Cook, 1998; Iyengar, 1991) and established in far-reaching freedom-of-information laws in a range of countries (Roberts, 2005). Individual narratives give voice to personal, intimate experiences in contrast to silence or abstract expert jargon, which, historically, has largely ignored these perspectives, and thus they potentially empower new groups and individuals and democratize public health debates (Coward, 2013; Frank, 2013; Mullan et al., 2006). In these standardized health stories, the media often and instinctively rally behind the patient/victim (Karpf, 1988; Morlandstø, 2006).

In general, individual stories are explanatory narratives incorporating cause-effect accounts which simplify the processes they explain, convey credit or blame, and distribute individual responsibility (Tilly, 2008). Hence, personal narratives represent certain types of reasoning, explanation and justification related to the individual's rights and claims, which often increase the attribution of responsibility to the authorities (Boukes, Boomgarden, Moorman & de Vreese, 2015). Public health authorities (Figenschou & Thorbjørnsrud, 2016), as well as medical doctors and nurses (Aarebrot, 2015) are critical towards such strong journalistic framing of health, at the same time as they claim that health journalists are easily influenced or manipulated by various interests and stakeholders with hidden agendas (Morlandstø, 2006, pp. 240–241). For medical professionals and authorities, the particular rhetorical power of personal stories (based on authentic experiences of the witness who lived the story) and the experiential legitimacy it gives the patient (Frank, 2013) represent a type of critique, which is difficult to counter in current emotional mediated debates (Beckett & Deuze, 2016; Wahl-Jørgensen, 2016). In essence, the perceived truth and authenticity coming from emotional involvement and personal experience challenge expert and professional arguments and insights (Wahl-Jørgensen, 2016, p. 135).

As mentioned above, patients' narratives pose different ethical challenges for health journalists than professional elite sources (Glück, 2016;

Morlandstø, 2006). In essence the Norwegian code of ethics (a set of normative guidelines adopted by the Norwegian Press Association) defines the overarching journalistic task “to protect individuals and groups against injustices or neglect, committed by public authorities and institutions, private enterprises, or others” (Code of Ethics, 2015, 1.5.). The code of ethics defines professional norms according to this overall aim – stressing editorial independence and critical distance from powerful influences. Furthermore, the code provides a strict privacy protection, which can only be breached if it serves the public good (Larssen & Hornmoen, 2013).

Historically the main emphasis has been on publishing and the end result (the journalistic text), but in recent decades, the need to be tactful throughout the journalistic procedure (including research, data gathering and source relations) has been added although the wording is vague (Larssen & Hornmoen, 2013, p. 82.). In critical reports where patients are interviewed to voice systemic critique, the watchdog role potentially conflicts with the need to protect vulnerable sources. This is stated through the imperative to show consideration for people who cannot be expected to be aware of the effect their statements may have, and to never abuse the emotions or feelings of other people, their ignorance or their lack of judgment (Code of Ethics, 2015, 3.8). It is the *ethical responsibility* of the journalist to judge whether their sources are ready to talk to the reporter, make their story public and meet the attention that may follow (Larssen & Hornmoen, 2013). Such a sensitive approach to vulnerability is arguably more urgent when dealing with people fighting illness and health issues, and their families. At the same time, critics argue that it is patronizing and a crude simplification to portray patients as a passive and powerless group, what Goggin (2009) labels *the charity discourse* in journalism. Different patients have various degrees of agency and control over their own story, representing a heterogeneous group with different motives, abilities and access to the public. What patients do share, in one way or another, is that they go through a difficult, challenging time, and particularly people in shock or grief are often more vulnerable than others.

## Method

This chapter analyzes how health reporters and editors reflect on employing a personal narrative in their reporting, based on in-depth interviews with 12 Norwegian reporters and editors who specialize in health. The author and a

colleague conducted semi-structured qualitative interviews with media professionals (health reporters and editors of medical media, 12 interviews). Additional interviews were conducted with leaders of influential patient organizations (3 interviews) who interact closely with health reporters in the process of finding and recruiting patients for the media.

The interviews were conducted in two rounds (March–April 2015 and April–June 2016) as part of a larger research project on mediated health debates. Each interviewee was asked to reflect on the key characteristics of health journalism such as sourcing strategies, narratives, ethical concerns and challenges. During the interviews, which opened as general conversations on health journalism in Norway, all interviewees brought up patient stories as important voices and compelling narratives. The follow-up discussions and critical reflections concerning patients as valuable, yet vulnerable sources comprise the data analyzed in this chapter. The interviews, lasting from 60 to 90 minutes, were digitally recorded, transcribed and de-identified. The reporters and editors interviewed, named Reporters 1–10 and Editors 1–2 to protect their anonymity, largely reflect the decentralized Norwegian media structure representing regional newspapers (3), the main national newspapers (4), the national broadcasters (3) as well as specialized health magazines (2). Their titles vary, and they are based on different newsdesks within the news organizations, but they were all responsible for health coverage in their newsroom at the time of the interviews. Whereas both of the editors were male, all of the interviewed reporters were women. The gender imbalance in our sample indicates that most specialized health reporters in Norway are women, a pattern found in most international studies of health journalists (see among others Tanner et al. (2015) and Viswanath et al. (2008)). In light of the gender imbalance, it should be noted that female health reporters are found to be more likely than their male colleagues to use human interest framing, controversial new information and the need to change behavior as story angles (McCauley et al., 2013).

The editors and reporters interviewed are all skilled communicators and experienced public speakers, potentially more able to control and frame the interviews than non-elite interviewees. To avoid formulaic well-rehearsed statements, the interviewers (who have extensive experience with interviewing media elites) carefully prepared follow-up questions and included examples from the media coverage. This methodological approach provided the



opportunity to get behind the general compliance with professional norms and ideals and to reflect on dilemmas in contemporary health journalism. Such dilemmas involve critical reflections on voice vs. exposure, criticism vs. campaigns, context vs. simplification – the ethics, production and political impact of individual narratives.

## **Analysis: Conflicted perceptions of a powerful tool**

### **Professional evaluations**

Overall, the interviewed health reporters and editors perceive health to be a topic, which is both universal and deeply personal at the same time, due to the perceived emotional proximity of the topic. As explained by a long-term health reporter: “It is immediate and close... for all. Everyone is affected in one way or another, themselves or their near family. It is an issue which touches people’s private sphere” (Reporter 2). Her colleague in a national broadcaster, emphasizes that health stories invite viewers to relate to the news: “[...] It always involves human beings - patients or next of kin or user – everyone relates to health in various ways throughout their lives” (Reporter 1). Health concerns life and death, and often documents crisis or trauma that could potentially harm the public or someone they love: “Stories of individual patients burn into our minds ... there are many of these personal stories and they are important because if it happens to one person, it has probably happened before, and it could happen again” (Reporter 4).

“What characterizes health journalism is *case journalism*: Journalism about people we can identify within a story.” This statement by an editor of a medical newspaper, illustrates how personal stories, most often those of the patients or families affected, were imperative to convey the perceived urgency and emotional proximity of health issues. The interviewees gave various arguments for including personal narratives, and employed them in various formats. Beyond identification, reporters stressed that individual voices and experiences can make complicated medical issues accessible for the general audience. According to a television health reporter: “I include a case in a news story because I have to exemplify the issues or explain to the viewers what it is all about... [...] It is not primarily to address politicians or the authorities, they know the topic, it is to get the public to understand what is at stake” (Reporter 3).

A reporter from a national newspaper, states that a case always has to add to and nuance the story to be included, “It needs to tell an important story and illustrate the topic in a representative way” (Reporter 9), a functionality or pedagogical argument for including personal stories<sup>2</sup>. Another, and related argument stresses the need to include those individuals who are directly affected by or involved in a story. To give those affected the right to be represented and a public voice. A senior reporter, who has specialized in health politics, explains: “We cannot cover health and ignore those directly affected – the healthcare system exists for the patients, and it would be very strange if they were invisible in the coverage” (Reporter 4).

Other interviewees present patient exemplars as journalistic tools to document systemic failure and maltreatment, “Because if someone does not receive proper treatment, the consequences can be dramatic and ensuing reports follow a very traditional script” (Editor 2). Particularly those interviewees who have covered health policies point out the rhetorical power of a striking, dramatic case, and how the right case (often understood as charismatic, deserving and vulnerable) could mobilize, draw political attention to a problem and push politicians to act on the issue. Illustrating the mobilization argument, an editor in a healthcare magazine explains that even though they are a specialized health sector publication targeting health professionals, they seek to employ the patient narrative rather than a professional or medical narrative to maximize impact and attention:

We framed a major investigative reportage on school nurses around the potential consequences for the pupils, as we documented how school nurses did not have time and resources to deal with the students’ health issues. It was a story about children and teenagers, but underneath it was also a story about health professionals, priorities and hierarchies, so there are always many agendas at play (Editor1).

A senior reporter in a major national newspaper, is worth quoting at some length:

The best stories, which are also well-read and of high quality, contain a case that represents and exemplifies an issue, which potentially affects many and that many identify with. And these reports are better when our story contributes to solving the issue

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2 Confer Pannti’s (2010) discussion on the journalistic rationale behind including emotional elements in the news.

at stake. [...] I remember there were two heart-wrenching stories, which demonstrated systemic failure after a large-scale merger in the hospital sector. A young, single mother who did not get proper testing, did not receive treatment soon enough and lost months of her life. The other, a young boy, a cancer survivor, fell out of the system and was not called in for his control... They made an uproar and were very moving stories to write. It not only affected me, but the entire newsroom and newsdesk were involved. Those are typical stories with an impact (Reporter 10).

In addition to pedagogical and political motives, a commercial imperative and push towards a more engaging, emotional and immediate journalism was a recurrent issue in the interviews. For the health reporters in commercial TV, a face or human exemplar is a requirement in every health story (a medium argument). Others, working in radio, print and online, explain that it has gradually become a demand from the editors and the newsdesk to include at least one case. In the online editions, particularly larger health features were systematically put behind the paywall to boost digital subscriptions. A reporter from a national newspaper put it this way: “Online, we have to trigger the reader’s curiosity... a universal, substantial topic with a broad headline is not enough, you need a compelling story” (Reporter 9). Consequently, health stories with a personal angle are prioritized on the front page, in the headlines and online, to attract much-needed audiences. The immediately felt connection to a compelling personal health story, thus exemplifies the strong belief within contemporary media and politics that people respond to emotions rather than facts or ideas (Ahva & Pannti, 2014; Beckett & Deuze, 2016, p. 3). Overall, there is a strong agreement among all interviewees that although personal stories have been part of health journalism for decades, patient cases have become more of an imperative in the contemporary media landscape.

Although they recognize the relevance of exemplars and employ them frequently, the interviewees are ambiguous towards the plethora of personal stories in contemporary health reporting. Many interviewees share a concern that personal narratives may move health news towards a simplistic, emotional, black-and-white style of reporting. This skepticism largely corresponds with traditional journalistic perceptions of emotions as unprofessional and symbols of low quality, tabloid reporting (see Pannti (2010) for discussion). The criticism further dovetails with media criticism from the medical community, which warns against the emotionalizing and oversimplification of mediated

health debates (Hinnant et al., 2013). The editor in a specialized paper, serves as a particularly outspoken representative of this position, describing Norwegian mediated health discourse as a *tyranny of cases*. He elaborates:

By a 'tyranny of cases' I mean how journalists obviously know that the emotional trumps the rational in many settings, and to hook the reader you need to bring in the emotional argument, right... And if you find elderly Kari, who has to live in the nursing home bathroom, then you know it will catch the readers' attention. But I believe that this tyranny of cases blocks systemic, more rational health reporting. And I see a tendency among journalists here, compared to other countries, of going too far in that direction (Editor 1).

Although all interviewees acknowledge the necessity of humanizing health news, most share a concern that the case narrative has become too dominant. Further, although all interviewed reporters argue that they strive to combine exemplars with written data, experts and background information, there is a shared concern that this is often demanding to put into practice. The pressure to include cases at a time when production resources are limited, deadlines shorter and news formats briefer, represents a common concern among reporters, who feel that the possibility to include substantial, thematic information in this situation becomes more limited. An experienced broadcast reporter pinpoints the challenges of routine health reporting:

Within the one minute twenty I have per story, I must squeeze in a case, the Health Minister and someone who thinks the minister is stupid [...]. So time pressure is the very prosaic explanation, but it does not entirely excuse the dominance of the personal, we do tend to fall in love with the case and then struggle to explain it in its proper context [...]. It is a generic challenge in journalism, but particularly in case-oriented health reporting, we should reflect on these issues: that it is actually not enough to tell only the individual story, but explain why and how it happened, what can be done differently and how experts perceive the issue (Reporter 4).

Some of the interviewees differentiate primarily between the media outlets and story formats in their criticism against emotionalizing and the lack of substance and context, distinguishing between quality and popular, specialized and general, broadcast and newspaper. Others argue that case-orientation is symptomatic of Norwegian popularized journalistic middle culture (Editor 1, Reporter 8). Some interviewees worry that the pre-defined roles and positions

in health reporting, where most stories are narrated from the perspective of innocent, deserving patient victims, can scare away medical professionals, scientists and experts from participating in the media, which again risk reducing the number of informative, specialist voices (Editor2).

Related to this, several interviewees are concerned that the media's tendency to foreground mistreatment and wrongdoing in the health sector, gives a skewed representation of the overall state and success of the healthcare system (Reporter 5). According to a reporter in a national news organization, the health sector presented in contemporary case-oriented health reporting shows crisis, the atypical single cases and tales of horrible conditions: "(I)t sounds like waiting lists are endless and patients fall between cracks all the time, which is not representative". (Reporter 2). Overall, these interviewees worry that the media may contribute to a public discourse on modern healthcare that does not allow risk, failure and death (Editor 2).

## Professional dilemmas

Patient cases are asked to share their experiences and feelings in a difficult life situation, first to a reporter, then with the general public. Even though being used as a human exemplar in the media potentially involves exposure of personal trauma and struggle, the interviewees agree that finding and recruiting individual cases is easier than expected. All the interviewed reporters from general news organizations use patient organizations or professional organizations (such as the doctors' organizations, nurses' organizations) as facilitators to find and put the journalist in contact with the right patient, medical doctor or nurse on short notice (Reporters 1–10). Other strategies to identify compelling cases or stories representing a topic or development include: Monitoring patient blogs or patient support groups in social media to discover new, gripping patient voices and recruit experienced patient voices (Reporters 1, 3, 9); sharing calls for particular experiences or stories in the reporter's social media networks (Reporters 3 & 10) or through the news organization's social media sites (Reporter 10); asking friends, family and colleagues if anyone knows someone who fits the case description (Reporter 9); and monitoring local and specialized media, for engaging individuals and unusual stories. In addition to the reporters' own initiatives to research and find patient cases, they are very often contacted by patients or interest groups and organizations with stories they want covered by journalists. According to a reporter in a regional newspaper, most of the individual patient

initiatives are simply put aside: “A lot of people contact us to complain and whine over everything they are dissatisfied with. We have a high threshold for pursuing these stories [...]. We are not medical experts and it is difficult for us to decide to what extent patients have received the wrong treatment” (Reporter 5).

Initiatives from organized patient interests represent a more complex challenge for the interviewees. In the interview setting all reporters declare that they shy away from pre-packaged information from professional stakeholders, although they may still use some of the information from these subsidized packages. Most relevant here – health journalists often outsource the direct recruitment of patient cases to external interest groups. For the interviewees who report that they have to produce more stories, for more platforms and more formats than 5–10 years ago, using patient organizations as facilitators is more efficient. Moreover, when patient organizations recruit patients they can select patients who are vocal and representative cases, who can articulate their feelings and experiences to a broader audience. Patient organizations further prepare patients for the interview situation and recruit patients who are ready to go public with their story. Through these practices health reporters “share” the responsibility of vetting patient cases with patient organizations, although the ethical responsibility lies with the journalists. The interviewed reporters underline the importance of a strong personal motivation for sharing patient narratives, and the motivation ranges from information about rare illnesses and diagnoses, health campaigns and education, public attention and mobilization for better treatment or living conditions for individuals and patient groups.<sup>3</sup>

The interviewed editors in specialized publications take a more critical position regarding the patient organizations’ role in current health coverage. These editors argue that the general news reporters can be naïve and turn a blind eye to how various interest groups form unholy alliances and “push patients in front of them” in the news media to fight for their own sector, political, professional or commercial interests (Editors 1 & 2). The interviewed reporters from the mainstream news media organizations acknowledge the fact that patient cases can be sponsored by the pharmaceutical industry or patient organizations and that this challenges their professional practices: They acknowledge seeing “the agenda, but not always the hidden agenda, and there are grey zones” (Reporter 1).

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3 Larssen & Hornmoen (2013) find a similar strong emphasis on the cases’ personal motivation to participate in their study of ethical dilemmas in the literary reportage genre.

Although the interviewees in this study take a critical, distanced stand vis-à-vis the pharmaceutical industry, they distinguish between various interest groups and tend to lower their guard in cooperating with patient organizations, particularly through wide-reaching professional collaboration regarding patient cases.

Moreover, patients' narratives pose ethical challenges for health reporters regarding how to balance being a critical reporter and a fellow human being. For one thing, the interviewees all argue that it takes time to approach, recruit and fact-check patient stories. A television reporter explains how she approaches new patient sources:

We spend a long time on the phone first. I let them tell their story and during the first conversation interesting details often come up: They have photos, they have home video recordings, they have a support network that can be a valuable source. We first spend time on the phone, and then it takes time to check the veracity of the story – that what they say is actually what happened [...] In difficult cases I have them sign an informed consent agreement (Reporter 3).

This approach to vulnerable patient sources, exemplified here, illustrates how an experienced reporter who routinely recruits and employs patient stories balances professional distance and human empathy – she engages and takes the time to listen to the patient's story, and through this process secures details and contacts necessary to verify the story.

In addition to traditional source work, the interviewed reporters also highlight the extent to which they try to prepare the patient sources for the coming media exposure. Again, talking on television is more dramatic for most sources than giving an interview to a newspaper reporter. At the same time, most stories today are published on numerous platforms, including online news platforms with user comments. A health reporter working primarily for television – explains that they have to use extensive resources in preparing individuals for what a personal interview actually implies in a hybrid media reality:

One thing is to prepare them to be on television – that we will come with a camera; how television can make a great impact; that the story will be online; your portrait; that you can be debated in the online commentary section, such things. We also make them aware that we cannot go beyond a friendly professional relationship after the story is published, because many people get very attached to us, particularly as

they share their life story [...] I have talked to many people who tell me things they have never shared with their wife or children, and they do it on television. It is quite intense (Reporter 1).

This quote also illustrates the tight bond that can develop between reporters and sources who share their personal story: For non-professional sources who have undergone traumatic or dramatic experiences, the reporter who takes time to listen can serve as a proxy therapist. The reporter's need to balance closeness and personal bonds with professional distance, is arguably more challenging when patients and other vulnerable sources share their personal stories and experiences. Another and related ethical issue, concerns the reporter's responsibility to protect vulnerable sources who cannot fully understand the consequences of sharing their personal details and private suffering. A reporter in a regional newspaper puts it this way:

Not everything is published, sometimes because the patient is worried and other times because there is a risk taking such private things public [...] I believe that if people are putting themselves out there and share their story, they should feel safe and know that we will take proper care of them (Reporter 8).

Many of the interviewees say that they meet patients with important stories who cannot be exposed in the media, because they are deemed too vulnerable or the topic is too sensitive. Overall, from the interviews it appears that it is the reporters who protect the sources, rather than push them to share more than they are comfortable with. Nevertheless, the editor of a specialized, paper claims that his competitors in commercially-oriented media organizations expose details of suffering and illness unfit for the public. He further stresses that such sensitivity regarding individual cases should not be restricted to patients and relatives, but also involve individual health professionals who speak out and serve as illustrative cases without always grasping the potentially negative consequences of their media appearance. He says:

My journalists have a clear obligation to follow our sources closely, also regarding the consequences media attention may lead to. So we work extensively to inform and involve them, and discuss what it implies, for instance, to be on the front page. So I would say that we take responsible decisions, even though it may be boring sometimes, and we also de-identify the cases sometimes. (Editor 1)



Most interviewees explain that they strive to prepare the patient for the level of exposure their story will get: whether it will be headlining, whether it will be on the front page, if it will be available online (forever), and whether it will potentially be shared in social media. Some reporters have routines to inform their patient sources as soon as they know the degree of exposure. Others are hesitant to give promises they cannot keep, as they know from experience that the size and placement of a story is rather unpredictable and out of their hands in the final stages of production. It is a dilemma for health reporters, who wish to prepare and follow up their sources, that they have limited means of control over the scale of a story, after they have completed their reporting tasks. Reporters disagree as to whether the interviewed patients are actually aware of what they are putting themselves into or not. A health reporter in a regional newspaper elaborates:

I can tell them that their story will make a mark in the paper – but it does not seem like they are really prepared for the level of exposure they receive, although they realize it will be a prioritized story. Many times I have experienced that you prepare them for something and then the end result is different. Something happened somewhere else in the world [...] It probably makes them disappointed or angry, but they do not complain to me directly, they complain to their friends and network. We rarely hear about it except from interest groups. We often get a sense of how satisfied they are, however, during the quote check (Reporter 5).

Whereas some prepare the sources for the massive attention they may get, other reporters emphasize the importance of preparing the patients for the ephemeral character of media attention – “that they are in the center of attention, and then they blink and it is over” (Reporter 1). The interviewees stress that how patients experience the publicity and exposure varies significantly, and that it is rather unpredictable. It is natural, yet ethically challenging, that the reporter-source relation and editorial responsibility to patient sources usually ends abruptly after publication. In contrast to documentary makers and reporters who follow their sources for extensive periods of time and often keep in contact with their sources after publication (see Larssen & Hornmoen (2013) for discussion), the health reporters interviewed here are news reporters who work regular shifts with short deadlines. None of the interviewees or the media organizations they work for have routines to follow up the patient sources after the stories are public. The reporters stress that they do not have

the resources to extend source relations and follow up on all their sources beyond publication. Many stress that most patients are very satisfied with gaining a public voice, arguing their case and doing what they can to make a difference. As explained by a television reporter:

You never know the consequences of sharing a difficult experience on television – but most people are very satisfied afterwards, because they receive a lot of feedback from friends, family and people they have not heard from in a long time. They get a lot of empathy and they feel it is easier to talk about things. It is very rare to find anyone who regrets the story or finds it difficult (Reporter 3).

On the other hand, interviewees are aware of the fact that patients who share their personal illness narratives can have negative experiences post-publication, related to all kinds of unwanted feedback (gifts, money, cures or hate mail) from healers, advocates for various medicaments or diets, suitors and trolls. In addition, patient stories can be shared and debated on various networked media outside of editorial control. The interviewed reporters are aware of these costs of exposing personal struggles, but acknowledge that although they try to prepare and protect the patients, the individual response and experience will vary.

## Conclusions

This chapter has investigated how experienced health reporters and editors reflect on the use of the *patient narrative* in current health journalism. Based on in-depth interviews, the present chapter contributes empirical insights to ongoing scholarly debates on the emotionalization of (health) journalism. The primary task here has been to illuminate the professional dilemmas, ethical considerations and critical reflections professional health reporters experience when they employ personal patient stories as journalistic cases and sources. For the interviewees the narrative represents a complex and complicated tool – it gives them the opportunity to attract audiences, gain momentum in political debates, and put politicians in the spotlight by foregrounding the human consequences of their policies. The patient narrative thus offers the interviewed reporters and editors an opportunity to merge their normative journalistic self-perceptions (defending the little man) with increasing commercial imperatives pushed upon them to attract dwindling news audiences. This organizational push towards more personal case journalism, put upon the interviewees by the editorial management and the newsdesk,

corresponds with the broader trends of a more individualized and emotional contemporary journalism (Ahva & Pannti, 2014; Beckett & Deuze, 2016; Coward, 2013; Wahl-Jorgensen, 2016). At the same time, health journalists' conflicted perceptions of the patient narrative reflect the ongoing debates both within the professional journalistic community and among journalism scholars on the role of emotions in quality journalism. Furthermore, criticizing journalists for emotion-alizing health discourses, is widespread across the health sector supported by scientists, health professionals and public health authorities.

The widespread, routinized practice of using patient organizations as case recruiters and facilitators, points to a potential risk for pressed reporters to become dependent on professionalized, powerful interest groups in their daily work, and moreover to outsource ethical concerns to these interest groups. Overall, the influence of organized patient interests corresponds with broader patient mobilization, increased patients' rights and the growing authority of lay expertise in current health debates (Nettleton, 2013). Having said that, the fact that the interviewed reporters lower their guard in relation to patient organizations calls for more analysis of the strategic initiatives and sector-wide co-operation between various stakeholders with common interests – argued in the media through compelling patient cases. This is particularly urgent to address in the current media situation, where reporters must produce more in less time. This points to the fact that patients represent a complex source category, ranging from innocent, vulnerable individuals, to well-connected individuals representing industry and political interest groups.

Finally, the interviewees highlight the delicate ethical dilemmas involved in giving voice and publicity to people in vulnerable positions. Health reporters and editors acknowledge the risk and unpredictability of public exposure, but generally do not go beyond the professional source-reporter relationship to protect vulnerable individuals, who make their experiences as patients public. This is primarily due to limited resources, continuous deadlines, and to a traditional critical approach towards all sources. This chapter has offered insights into these considerations and reflections from a professional journalist perspective. To fully analyze and comprehend the cost and potential of making one's medical story public, it is necessary to conduct more studies of how vulnerable sources themselves experience this process.

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