

# Text and Context

## *The Patient as Text - Revisited*

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As a tribute to the Norwegian literary scholar Petter Aaslestad's *The Patient as Text. The Role of the Narrator in Psychiatric Notes, 1890-1990*, the research group Health, Art and Society (HAS) at UiT The Arctic University of Norway organised the symposium *The Patient as Text - Revisited* in autumn 2018. Aaslestad explores in his book from 1997 around 150 patient files from a Norwegian psychiatric hospital written between 1890 and 1990. Applying narratological categories, he analyses who is speaking in these reports, which perspectives are used, and in which ways those perspectives are reproduced. In this way, he unravels how patients diagnosed with schizophrenia are narratively present or absent in their own medical files and how the mental health professionals, as constructors of these narratives, are surrounded and affected by ideological and medical changes.

*The Patient as Text* was a very important, early Scandinavian, contribution to the field of the medical humanities, which originated in the United States in the late 1970s. The medical humanities emerged in response to the increased biomedical approach to medicine. Using the humanities and social sciences as central methodological and theoretical approaches to better understand the complexity of everyday medical practice, shows the importance of the humanities and social sciences for both established professional educational programmes and major

challenges in society. Rita Charon, has developed a model in the field of narrative medicine that includes literature and narratology in the study of medicine. The aim is to enhance understanding of patients' stories and thus improve clinical practice. Narrative medicine originated around the year 2000 at Columbia University, and today the field is included in the curriculum in several American and some European medical programmes, including that of the University of Southern Denmark. In Norway, however, narrative medicine has not yet gained a formal foothold, although several people have voiced support for it.

*The Patient as Text* was a pioneering work, with its use of a narrative model as a methodological tool on a hitherto unorthodox type of material within comparative literature. Aaslestad gives prominence to the voice of the doctor and/or therapist, but he examines them in a critical manner. By subjecting the therapists' descriptions of their patients to a critical gaze, Aaslestad conducted an important exercise. Since antiquity, physicians have written about their patients as part of their clinical practice. Within the genre referred to as psychopathography, doctors of more or less famous patients have attempted to explain their patients' character traits from an illness perspective, whether they be brilliance and/or madness. Freud's work on Leonardo da Vinci from 1910 is often mentioned as an example of this genre, but the Norwegian psychiatrist Nils Rettestøl's *Store tanker, urolige sinn. 21 psykiatriske portretter* (Talented Thoughts, Troubled Minds. 21 Psychiatric Portraits) from 2006 is a modern example in which different historical characters such as Vidkun Quisling, Edvard Munch and Amalie Skram are subjected to a post mortem psychiatric analysis.

*The Patient as Text* is interesting in a literary scholar's perspective because it demonstrates the way in which narratology as a methodological approach may be applied to other literary fields than fiction, as well as for those who work with patient records on a daily basis in their professional life. It still holds this relevance. For example, a recently published doctoral dissertation from the University of Oslo by Guri Aarseth shows, how GPs' medical certificates studied as texts constitute a particular genre whose purpose is to persuade healthcare bureaucracy to provide support to patients. The thesis shows, that GPs' medical certificates are based on value judgements, which does not represent a challenge in itself: "*It can be a problem, however, when the rhetoric replaces professional information that may justify important decisions, such as the allocation of social goods*" (Aarseth 2019: 65). It is interesting that this socio-economic conclusion stems from the literary method of close reading (Aarseth 2019: 45). In a related article, Aarseth and her co-authors argue, that this type of problem should be included in the education of doctors to

raise their awareness of how their work is embedded in a textual genre with its associated demands and expectations. The authors conclude by recommending training in writing in professional education “preferably involving humanities professors” (Aarseth et al. 2017: 11). Aarseth’s perspective is indebted to Petter Aaslestad’s book where he shows how patient records are not transparent and unambiguous but rather value-adding and normative. Aaslestad’s work demonstrates how practitioners’ descriptions of their patients affect the way in which psychiatry attends to the patients: “This is therefore not primarily a book about patients, but about the gaze they are subjected to. And the gaze strikes back. It is a book about psychiatry as a societal and linguistic institution” (Aaslestad 1997: 12).

When the research group Health, Art and Society decided to mark the (delayed) twentieth anniversary of the publication of *The Patient as Text*, we wanted to emphasise some of the changes that have taken place within the field of patients’ stories. In the wake of Aaslestad’s publication, the increase in autobiographical patient narratives, both analogue and digital, has been particularly prominent. Patients have begun to stand out, not just as text, but also as producers of text. Consequently, the purpose of the symposium in 2018 was, in the same fashion as with Aaslestad’s book, to increase the focus on what it means to be a patient. However, the perspective in the symposium was primarily that of the patients and not texts about patients mediated by others. A majority of the contributions revolved around autobiographical patient stories or stories told by close relatives. Such stories are referred to as autobiographies or biographies, illness literature, testimonial literature (von der Fehr 2009: 09) or more generally as “the new biographical self-exposing literature about illness” (Økland 2019), or more precisely as pathographies. In what follows, we will, therefore, give an account of this genre, including both its background and its development.

## Testimonial, angry and ugly pathographies

The term *pathography* comes from Greek, and is a composite of Πάθος (‘pathos’), meaning ‘passion’, ‘emotion’, and γραφή (‘graphē’), ‘writing’, that is, *that which is written about passion/emotions/suffering*.<sup>1</sup> Anne Hunsaker Hawkins defines pathography as a type of autobiography/biography describing personal experience of illness, treatment and sometimes death (Hawkins 1994: 1). She particularly connects the term to physical illnesses but emphasises that it may also include mental illnesses (Hawkins 1984: 249). In her seminal work *Reconstructing Illness*.

*Studies in Pathography* from 1999, Hawkins writes that the genre became popular in the US around 1950. The first Danish and Swedish pathographies emerged in the late 1960s, whereas the first Norwegian pathographies were published in the mid-1970s. Although the pathography as an autobiographical genre is relatively new, it has had its precursors.<sup>2</sup> The pathography is just one of several kinds of life stories that have been popular at least since the eighteenth century. Many of these life stories are referred to as confessional literature, a term that can be traced at least as far back as Saint Augustine's *Confessions* from c. 400 A.D., which has been described as the first autobiography in Western civilisation (Berg Eriksen 2009: xviii).

Although the modern pathography is relatively young, the genre has already undergone several stages of development. Hunsaker Hawkins has a dynamic view of the pathography genre. She outlines development in the genre from the 1970s to the 1990s, where she proposes three stages: "*If we use authorial intent as an organizing principle, pathographies tend to fall into three groups: testimonial pathographies, angry pathographies, and pathographies advocating alternative modes of treatment*" (Hawkins 1999: 4). Particularly the two first categories are of relevance today. Hunsaker Hawkins understands testimonial pathographies as: Those that document illness, supplement medical records, and offer advice and support to readers. An interesting example of a testimonial pathography is Per Hansson's *Den siste veien* (The Final Path) (1978). *Den siste veien* tells the story of the author's own deep and biographically rooted depression but dwells particularly on the fate of the 22-year-old seriously ill cancer patient Ola Smedsgaard. Ola is distinguished by his bravery and lack of bitterness over his illness and communicating his illness experience becomes an activity that creates meaning in his life. Ola's knowledge of death becomes his testimony:

*"I pondered how we could give him greater meaning in everything: the path towards death, his path, and I contacted him soon afterwards and said, 'Ola, I think you can do something for research into death, into dying, since you have the courage to look it in the eyes and the intellect to communicate it'"* (Hansson 1978: 52).

Several times Ola mentions his love for his family, but also his grief at being unable to have his own children. He feels that he has moved off the "starting line" (Hansson 1978: 129) and, therefore, urgently wants to leave behind "*permanent traces on his path towards death*" (Hansson 1978: 8).

An example of a so-called angry pathography is one of the first Norwegian patient books, namely Thorstein Jacobsen's *Farlige menn i hvitt* (Dangerous Men in White) (1975). The book is autobiographical and, as the title shows, is critical of the health care system and of doctors in particular. It was debated for considerable time on television and other mass media and was named the debate book of the year. It was publisher Dreyer's bestseller in 1975 and also sparked a debate in Sweden and Denmark. *Farlige menn i hvitt* is a critique of aspects of modern medical practice but also deals with the ability and willingness to live with a chronic illness without ever giving up. Another critical example of an angry pathography was Peter Noll's *Diktate über Sterben und Tod* (In the Face of Death) (1984). Noll was a professor of criminal justice in Mainz and Zurich and the book attracted attention on publication, partly because Noll chose to refuse treatment for cancer and wanted control over his own life and death. Angry pathographies are oriented toward an external object that causes negative feelings in the patient, mostly the healthcare system as is the case with both Jacobsen and Noll. In recent years, however, there seems to be a trend where pathographies focus more on internal anger, grief or fear. The many testimonial works seem to have evolved into a variant where the focus on the sick person as an exceptional hero is toned down in favour of everyday portraits where feelings such as fear, bitterness, grief, envy and anger are made explicit. We have chosen to call these texts *ugly pathographies* indebted to Sienna Ngai's seminal work *Ugly Feelings* (2006). Negative feelings, not only include a negative response to characters and one's environment, but are also somehow aesthetically unattractive and unfruitful. Ngai writes in the introduction of her work:

*"For in keeping with the spirit of a book in which minor and generally unprestigious feelings are deliberately favoured over grander passions like anger and fear [...], as well as over potentially ennobling or morally beatific states like sympathy, melancholia, and shame [...] the feelings I examine here are explicitly amoral a nonchatarctic, offering no satisfactions of virtue, however oblique, nor any therapeutic or purifying release."* (Ngai 2006: 6)

Such negative feelings have previously been underrepresented in fiction in favour of "grander and more prestigious passions" (Ngai 2006: 10). In patient narratives also, we find that bitterness, depression and anger have been communicated less than acceptance and harmony. In terms of the sociology of literature, this may be because publishers prefer positive and constructive stories that appeal to a broad

der readership. In terms of reception theory, this is reflected in authors finding alternative ways to communicate ugly feelings. Sometimes this is solved with the description of a parallel universe. One example of this is the debut work *Der bor Hollywoodstjerner på vejen* (Hollywood Stars Live in the Road) from 2016 by the Danish author Maria Gerhardt, which deals with having cancer but is also about parties, drugs and a long love affair between two women. The book is linked to places that represent the ugly and beautiful emotions of the sick person, respectively the hospital in Copenhagen and the exclusive suburb of Hellerup where the main character Maria eventually moves. She is a “coper” (Gerhardt 2016: 86). But when she meets another sick person or hears an unfortunate comment, her control slips and the ugly feelings come to the surface:

*“You can’t be lesbian, sick and sad. That’s one category too many. If I could at least have one good week and be the smiling sick person. If I came along full of energy, gave people long hugs and had an intense look in my eyes. If I’d just been in the paper. But I’m sitting here with a muzzle on, saying nothing, giving nothing.”* (Gerhardt 2016: 87)

The illness encourages Maria’s selfishness. Maria’s cancer narrative demonstrates no positive values and she makes no sense of her illness experience: *“I’ve read about severe illness as providing existential freedom, and I’m just waiting for this freedom. I’ve really been so very ill that I should have learned something. But my slate remains quite clean”* (ibid.). The illness does not give Maria any new insight, any grand life project or any better traits of character. Breast cancer makes her self-absorbed, exhausted, afraid and more and more “extinguished” (Gerhardt 2016: 161).

The possibility of communicating one’s illness experience without using the publishing industry may be one reason why ugly pathographies have become increasingly frequent. The rise of digital platforms has changed the ways people communicate about illness. Around the year 2000, the number of digital patient narratives increased dramatically due to the growth of Word (Tjora & Sandaunet 2010). In Norway alone, there are 156 registered patient associations and several of these have links to personal narratives. If we examine just three of these patient associations (The Norwegian Cancer Society, Neuro-Muscular Disorders Association of Norway and the National Centre for Knowledge through Experience in Mental Health), we find more than 250 online patient narratives. These digital stories are much less edited than published books and ugly emotions occur frequently. One example is a blog by the Norwegian Marit Ulrichsen, “I det syke

hjørnet” (In Sick Mode). Ulrichsen died of cancer on 30 January 2013 and in a blog post written scarcely a month before, she describes the anxiety her illness has caused her:

*“I cry a lot before midnight, I cry when I wake up at night, before bedtime, when I wake up, when I go to bed. For no reason, can’t put it into words, don’t know where it comes from. Nothing but fear. Of dying, not waking up, losing my life, losing tomorrow, not seeing that the Christmas decorations have been put back properly in their boxes, or being afraid that none of the children are prepared for what’s coming, that we haven’t talked enough about it, explained enough.”*

The explicit openness around so-called ugly feelings makes this a disturbing read. Marit Ulrichsen’s blog appears authentic in a different way from many pathographies published as books, including those based on blogs or other online illness stories. One aspect of the appearance of ugly pathographies, is the frequent description of apparently mundane everyday events that may be due to the lack of editing. It may also be because today’s so-called reality literature has made it legitimate to focus on the subject and the subject’s experiences as meaningful; in this way, telling about one’s own, often intense yet trivial, experiences feels neither embarrassing nor invasive. It is, therefore, also legitimate to share less flattering experiences such as bitterness, envy, grief and rage. This means, that the self as portrayed in the pathography genre today appears as less homogeneous and harmonious than previously. Perhaps the result of this diversity is a more authentic self. As early as 2011, Angela Woods wrote about the need to be critical of the truthfulness of illness descriptions. Discussions in recent years of ethical issues related to character portrayals in reality literature and the emergence of fake illness blogs, including that of the Australian Belle Gibson, whose blog about a number of serious illnesses went viral, have shown that truthfulness is an ever-increasing challenge due to literary trends and digital developments.

## Unnatural narratology and critical narrativity

While it is relatively easy to see how the humanities have contributed to the medical field, it is more difficult to determine what medical humanities have added to the humanities disciplines. Specifically, the textual corpus has been expanded, and the traditional preference in literary science for fiction has been supplemented

with professional texts, such as patient records and medical certificates. Further, digital narratives are produced by patients or their relatives who are non-professional writers and choose social media instead of publishing houses to convey their messages. In other words, this is a movement away from what the literary sociologist Robert Escarpit in the 1950s called artistic literature towards popular literature. Merete Mazzarella also touched on this question of contribution in an essay with the promising title *"How my encounter with medicine has alerted me to new possibilities in fiction"* (2004), but the answer is cautious and personal: *"If the reading of literature can provide medical students with insight into the meaning of subjectivity, ambiguity and ambivalence, I have also thought that for literary scholars it is good to be reminded that one can also think in terms of objectivity, measurability and predictability"* (Mazzarella 2004: 67). Narratologist Shlomith Rimmon-Kenan came closer to a more substantial viewpoint in the article *"What can narrative theory learn from illness narratives?"* (2006), where she shows how illness stories are suitable literary material for challenging, and possibly developing, narratology. This applies, for example, to the question of randomness, which is a vital element in these stories and which biomedicine is also confronted with: *"Narratology gives insightful accounts of order but has no tools for – and no interest in – an analysis of randomness"* (Rimmon-Kenan 2006: 245). Rimmon-Kenan identifies four main areas in which illness narratives can contribute to narratology: *"the complex interaction between the collapse of the body and that of the narrative, the problem of narrating the unnarratable, the author-reader relationship, and the subsequent implications for narrative ethics"* (Rimmon-Kenan 2006: 241).

Some of these approaches have been discussed in narratology in recent years. One example is the question of developing a conceptual apparatus to describe what does not seem logical or probable; this has been considered in terms of "unnatural narratology", a field which deals with texts that run contrary to general expectations about the world and associated cognitive parameters (Alber et al. 2010: 114). Pathographies often deal with first-hand experiences of dying, and sometimes the borderline between life and death is crossed, providing access to an otherwise closed place: *"[W]e seek in narrative the knowledge of death that life denies us"* (Gygax 2015: 43). Unnatural narratology has not been specifically concerned with disease narratives, but both older and more recent pathographies contain examples of established notions of what death entails that are interesting to discuss from a literary perspective (Nesby 2019). In other words, unnatural narratology appears relevant to the study of illness narratives, especially in relation to the growing field of medically unexplained symptoms (MUS), where bodily signals

cannot readily be translated into medical vocabulary, which is clearly problematic for patients and their family members. Unnatural narratology preserves the concept of narrativity, while the corpus under study calls for greater flexibility in terms of a classical understanding of a narrative (and a life) as linear, transparent and meaningful.

Another field in which medical humanities have undoubtedly provided an interesting and critical conceptual discussion is linked to the concept of narrativity. Narrativity is rooted in both the humanities and the social sciences. A key figure is the psychologist Jerome Bruner, who in his article "Life as Narrative" (Bruner 2004) in *Social Research*, argues that there are basically two ways of thinking: the narrative way of thinking establishes knowledge at the specific and individual level, while logical-scientific thinking seeks to transcend the individual and establish knowledge in general terms. In the study of illness narratives, the long-prevailing view has been that the narrative offers the key to how people experience, understand and cope with illness and medicine. Such narratives have provided meaning, not least positive meaning. In her work from 1999 on autobiographical patient narratives, Anne Hunsaker-Hawkins wrote that illness stories attempt to "restore to reality its lost coherence and discover, or create a meaning that can bind it together again" (Hawkins 1999: 2). However, such a harmonising view of narratives has been challenged, also specifically in relation to the medical humanities and Angela Woods unequivocally states that narratives are not only based on harmony: "Narrative is not, and never has been, innocent; it is not, and never has been, inherently oriented towards the good" (Woods 2011: 75). Narratives are also not transparent and general but are based on inherent historical, gender and cultural criteria that are, however, rarely discussed.

Like Rimmon-Kenan, Woods also warns against the tendency to emphasise stringent, transparent and intuitively meaningful illness narratives. This is an objection that has been raised in recent years by several researchers. One approach is that of Sara Wasson in her article "Before narrative: episodic reading and representations of chronic pain" (2018). Wasson introduces the idea of sequential reading which, rather than relying on context and temporality, focuses on fragments and a here and now experience of illness stories: "I argue that some illness experiences may require a parallel reading practice, reading less in search of narrative coherence or self-authorship and more interested in the value of textual fragment, episodes considered outside a narrative framework" (Wasson 2018: 106). Such a view of reading can also encourage expressions that are more lyrical in which immediacy, scarcity and

visuality are important lyrical tools, yet they still convey a density of meaning equivalent to that found in illness stories in traditional prose.

## Ordinary people, celebrities and the future of patient stories

In the article “Heroic Life and Everyday Life” (1992), the British sociologist Mike Featherstone introduces factors that may have contributed to the growth of the pathography. Without mentioning illness stories in particular, Featherstone points out a societal phenomenon that can still be said to be relevant to the interest in the pathography genre:

*“Hence in the popular media there is a constant celebration of ordinary heroes, those individuals who are thrust into a situation of extreme physical danger in which they show extraordinary courage such as risking or sacrificing their lives to save other people. It is this chance element, that fate might intervene and shatter the everyday order of the happy life and thrust any individual into a situation beyond his control which demands a response, which is fascinating to the public, who cannot but help wonder ‘How would we respond to the test?’” (Featherstone 1992: 167)*

In parallel with the interest in stories about ordinary people, however, we find a remarkably strong focus on celebrities who present their illness stories. The field of celebrity studies that emerged around 1990 has recently shown increased interest in the way celebrities communicate mental or physical illness. Informing readers about important medical issues may also enhance celebrities’ credibility. A well-known international example is the Angelina Jolie effect, where the American actress made public her decision to remove both breasts due to a hereditary gene defect (MacGraw 2018, Troiano 2017, Bragazzi 2015). In Scandinavia, names such as Ulla-Carin Lindquist, Maria Gerhardt and Gunnhild Stordalen can be cited as examples of how celebrities can increase awareness of and testing for specific diseases. This phenomenon is emerging in parallel with and in contrast to the development of evidence-based medicine (Lerner 2009: 3). The potential of the illness narratives of popular celebrities to influence ordinary people’s medical decisions is an ongoing trend that has been little explored. A key feature of celebrity

culture is how these people are portrayed as part of a “democratic aristocracy” (Gamson 2001: 1579) by being presented as both identical to and different from the public. The tendency to promote celebrities’ health can be understood as an effective way to achieve greater democratic identity. Sharing their illness stories also creates authenticity by displaying a vulnerable, less polished side of celebrities than the glossy image the mass media traditionally presents: *“The question of what a celebrity is ‘really like’, what kind of self actually resides behind the celebrity image, is a constant, whether in the form of tabloid exposes, behind-the-scenes reporting, celebrity profiles, or fan activities such as autograph-seeking”* (Gamson 2001: 1580). Further, the way celebrities promote health information in light of their own illness experiences, via blogs or books, as well as their use of the media, is interesting and complex and remains to be researched internationally and more specifically in Scandinavia.

Patient stories appear frequently on television and in newspapers and magazines as a result of public interest in such stories (Walter 2010) and illness blogs have become an established sub-genre (Podnieks 2016, Nesby & Salamonsen 2016). But despite a certain academic interest in different aspects of patient stories in recent decades, due to the clearly growing number of written illness experiences from the viewpoint of patients or their relatives, these stories still represent a somewhat uncharted territory, especially in the field of literary studies (Rimmon-Kenan 2006, Stene-Johansen & Tygstrup 2010). Pathographies are often narrated by ordinary people who are neither trained authors nor intellectuals, and they are not necessarily valued as grand literature, regardless of their literary quality. Illness blogs, SMS and diary entries call for literary concepts meaningful to the small-scale format of these texts and “small stories” is a sociolinguistic concept that seems fruitful (Bamberg 2006, De Fina & Georgakopoulou 2015, Federhofer 2018). Other aspects of patient stories need to be elaborated on: What are the literary techniques used in these formats, how do they differ from older, perhaps more traditional formats and what are the thematic implications of a day-to-day description of one’s own illness, as in patient blogs? How has the communicative aspect changed between older and contemporary patient stories, and how are e.g. relatives and friends depicted? Illness narratives must not only be studied as literature, but also in relation to literary production and communication. This is a large and complex field where the study of illness narratives could in fact be a focal point for modern literature, the study of communication and textual understanding. The question of why these stories attract so many readers has yet to be explained and explored, either as a literary or a cultural phenomenon. Rita Felski

argues for a “neo- phenomenology” that can be used to explain the historical and social dimensions in capturing the attractiveness that patient stories have had and will continue to have for their readers: “*If historical analysis takes place in the third person, phenomenology ties such analysis back to the first person, clarifying how and why particular texts matter to us*” (Felski 2008: 19). In an article from 2006, Jan E. Frich mentions that the reader of patient narratives should ascertain whether there are financial factors or other interests that might override the patient’s voice (Frich 2006: 45). This is an aspect, that has become even more relevant today with the blossoming of illness blogs, where the blogger often receives sponsorship and/or grants. What this means for how these blogs are created, what effect it has on readers, and how it affects the message are all factors that remain to be researched

## Why revisit the patient as text?

Despite the popularity of the pathographic genre in recent decades and despite the various phases it has undergone, no collection of articles dedicated to the pathographic genre has appeared until now. Whereas Aaslestad was highly innovative in bringing the medical journal and the therapists’ views of the patient into the field of literature, the contributions in this special issue all have in common that the patient’s experiences are in the forefront, rather than those of the doctor or therapist. This shift of focus illustrates the development over the past twenty-odd years since Aaslestad’s *The Patient as Text*. Most of the topics touched upon in this introduction are discussed in the various contributions in this special issue, others reflect areas in the field of pathography that are still far from exhaustively discussed. Others again remain yet to be studied. Overall, this volume reflects the diversity of subtopics under the main head genre pathography. Moreover, the contributions illustrate the interdisciplinarity of the field. Arranged into five sections on 1) historical medical humanities, 2) mental illness, 3) patient stories in the health and education professions, 4) the cancer patient in contemporary literature and 5) patient stories in the digital media, the contributions in this special issue bring new insights to the field, challenge established theories and methods and suggest new trajectories and topics yet to be explored. The aim is to bring new knowledge, but also curiosity, to the field of illness stories in the hope of expanding and developing the discipline further.

This special issue starts with three articles that will comprise a historical medical humanities section. In her article ‘Pain and Epiphany’, Cathinka Dahl Ham-

bro traces the pathography back to the Middle Ages and beyond, and discusses whether the English mystical writer Julian of Norwich's work *Revelations of Divine Love* may be read as an early patient text. Using Anne Hunsaker Hawkins' notion of English seventeenth-century conversion narratives as precursors to the pathography as a starting point, Hambro moves further back in time, and suggests, after dissecting the term pathography and examining its meanings, that the term may even be used about the passion narratives in the New Testament Gospels. Moving on to the Middle Ages, Hambro explores the significance of pain in medieval religious culture and discusses whether we may learn something today from the way in which people previously found meaning in pain instead of considering pain as an evil that needs to be eradicated.

Moving on to the romantic period, but still in England, Paula Ryggvik Mikalsen has studied the character Henry Tilney in Jane Austen's *Northanger Abbey* (1817). At a time when being too preoccupied with reading was considered an illness, Henry Tilney sets out to cure the novel's protagonist Catherine Morland of her reading illness, finding her too caught up in Gothic literature. However, although most research on this novel has focused on Catherine Morland, Mikalsen discusses the way in which literature unintentionally eventually becomes a cure for Henry Tilney that helps him deal with his own trauma while he fails in his initial attempts to cure Catherine. *Northanger Abbey* is a Gothic satire, and Mikalsen moreover demonstrates a connection between Gothic literature and modern patient stories, the two sharing many of the same literary tropes and motifs. As far as the editors are aware, this interconnectedness has not been previously discussed and sheds new light on both patient stories and Gothic literature.

Silje Warberg's article on medicalised literary criticism in the *Fin de Siècle* period explores the role of Norwegian medical doctors Johan Scharffenberg and Henrik Dedichen as 'medics-as-critics' in the public debate in the late nineteenth and early twentieth centuries. In the period under discussion, literary criticism made up a significant part of the public debate in Europe, and medical tropes, imagery and terminology were widely used in the discussions of literature, but also with reference to the decline and decadence typical of the period. Medical analogies were used in discourses concerning science, culture and society, referred to by Warberg as *medicalised literary criticism*, a phenomenon that she describes as a "*tendency toward medicalization in the European public sphere throughout the latter half of the nineteenth century, through which a large variety of human problems were (bio)medically explained.*" Warberg uses Scharffenberg and Dedichen and their contributions to this public debate as a case study for this phenomenon. In doing so, she demon-

strates how Scharffenberg applies his medical expertise to literary texts by writers such as Jonas Lie, whereas Dedichen uses texts written by his patients in order to discuss mental illness in the public sphere. But Dedichen also uses his expertise to publicly address the mental health of writers such as August Strindberg, based on their literary works. This bridges the historical section and the following section on mental illness and institutions, in which the first article also discusses literature that goes somewhat back in time and could equally well belong to both sections.

Ingrid Løkholm Ramberg presents an analysis of Amalie Skram's novel *Professor Hieronimus* from 1895, one of Skram's so-called hospital novels. The story revolves around the protagonist Else Kant and her stay at a mental hospital, where Kant strongly criticises the way she is treated. Since Skram herself was hospitalised in mental institutions and was fiercely critical of her own treatment, the novel has been read as autobiographical by general readers and scholars alike. Drawing on theorists such as Shoshana Felman, Erving Goffman and Giorgio Agamben, Ramberg discusses the way in which Else Kant is becoming more and more institutionalised during her stay at the mental hospital and consequently secluded from society. Looking particularly at animal imagery in the novel, Ramberg explores how Skram demonstrates Else Kant's seclusion and institutionalisation through the use of these vivid mental images.

In "Chaos Narrative and Experientiality in the Graphic Memoir: The Case of Thomas H. Nøhr's *Cirkus*", Lasse Gammelgaard brings the reader into the graphic world of literature. This autobiographical cartoon is an illness story depicting the author-illustrator's encounter with the health care system when suffering from depression and burnout. In his discussion, Gammelgaard uses Arthur Frank's concept of chaos narrative as a starting point. Frank argues, that when a person is struck by illness, the chaos it brings about in the person challenges the narrative plot of a life story, and illness, therefore, in Gammelgaard's own words, "*poses a challenge for the construction of a narrative*". By combining Frank's notion of chaos narrative with other qualities of narrative such as experientiality and tellability, Gammelgaard argues that the graphic novel challenges Frank's dismissal of the chaos narrative as 'proper' narratives because they often lack what we generally consider a 'plot'. According to Gammelgaard, Frank, being too reliant on the concept of a 'plot', fails to see how narratives may be formed in other ways that put the plot in the background of the story, while the story may nevertheless constitute a narrative.

Hanne Sæderup Pedersen looks at semantic features in her article “A typical patient with depression? A comparative linguistic analysis of accounts by general practitioners and psychiatrists”. Although closer collaboration between general practitioners and psychiatrists has been encouraged both in Denmark and internationally with regard to patients suffering from depression, the ways in which these two groups of medical practitioners describe and communicate with their patients vary to such an extent that it makes collaboration challenging. The two groups seem to understand the diagnosis differently and thus have divergent perceptions of treatment, and there seem to be cultural differences in the two sectors that affect the way in which practitioners describe patients. As a contribution to the field of social medicine, Pedersen provides a linguistic analysis of health care interviews as an alternative method for bridging the gap between the two groups of professionals under discussion.

Focusing on another profession, Lise-Mari Lauritzen discusses the use of literature in the Norwegian classroom for health purposes. The Norwegian government has announced that a new curriculum will be launched in which public health and life mastery will be introduced as a topic in all subjects as a response to the increasing number of young people suffering from mental health disorders. Although the term ‘narrative medicine’ has primarily been used precisely within the field of medicine, Lauritzen suggests that a combination of literary studies and *narrative medicine* may also be applied as a method in the classroom in order to address the issues of public health and life mastery. The key notion in her discussion is narrative empathy, and through a reading of Carl Frode Tiller’s 2017 novel *Begynnelser (Beginnings)*, Lauritzen demonstrates how literature may increase the reader’s empathy. Using Rita Charon’s model of close reading, students may learn to identify with the literary characters and their situation and empathise with these, which may consequently help improve students’ health and sense of life mastery. She thus takes narrative medicine out of the field of medicine and into the high school classroom and shows how the method of close reading, in order to increase empathy, may also be used in other disciplines and settings.

Back to the original setting – medicine – the two following contributions also deal with narrative medicine and the effects of creative writing in the field of health. Still, within the world of education, Sif Stewart-Ferrer and Anders Juhl Rasmussen present a new course in narrative medicine that has become an obligatory part of the curriculum for medical students at the University of Southern Denmark. The authors also point out that, there is a relatively large number of theoretical works arguing for the value and effect of narrative medicine, such as

courses in creative writing and close reading for medical students, to enhance empathy and improve patient care. However, there are comparatively few empirical studies that provide evidence of the positive effects of such medical humanities education. There is thus a divide between theory and empirical data, not because the empirical data contradict the theory, but rather because of the lack of empirical studies. Stewart-Ferrer and Rasmussen present in their article a review of the existing empirical studies thus far and give an account of what these studies say about the impact of narrative medicine, i.e. close reading of literature and creative writing, on health care students. This impact is, however, difficult, if not impossible to measure. Whether medical students become better practitioners through close reading of literature and creative writing is ultimately shown in the effect they have on their future patients.

Helle Ploug Hansen, Sara Seerup Laursen, Ann-Dorthe Zwisler and Anders Juhl Rasmussen have observed and interviewed cancer patients participating in creative writing workshops as part of their recreation programme. The workshops were inspired by Rita Charon's narrative medicine model, and Hansen et al.'s point of departure is Charon's argument that creative writing and close reading can have therapeutic effects. Based on their observations, Hansen et al. discusses how the patients experienced the creative writing workshop with particular regard to whether it helped increase their well-being and boost their communicative skills. In addition to the creative writing process, the workshop also included the patients reading aloud their own texts written in the workshop. Hansen et al. found that the patients experienced both the writing and the reading aloud as highly positive, and that it helped them cope with their disease and increased their self-esteem. The writing helped the patients communicate their experiences, whereas the reading aloud enabled them to share their experiences with the other participants, who together formed a small close community in which everyone was in the same situation.

Since cancer is one of the most common diseases in the Western world today, stories about cancer naturally take up much space in a special issue on patient texts. The following section on cancer in contemporary literature consists of four articles that all revolve around either professional doctors or authors who write about experiences with cancer. The best-selling American book *When Breath Becomes Air* is the topic of May-Lill Johansen and Linda Nesby's article 'Why do we read illness stories?' The author of this autobiographical book, Paul Kalinithi, was a neurosurgeon diagnosed with lung cancer. He died in 2015 aged 37, and his illness story was published posthumously in 2016. Johansen and Nesby ask

why illness stories have become so popular in recent years. They use *When Breath Becomes Air* as a case study to explore this question, partly because this autobiography became a major best-seller in the US, and partly because it illustrates perfectly some of the general characteristics of the pathography that make this type of literature attractive to a wide readership. In demonstrating this, they apply Rita Felski's four concepts of knowledge, recognition, shock and enchantment, as presented in her seminal work *The Uses of Literature*. In applying Felski's literary theory to Kalinithi's memoirs, however, they also find that her theory is not only relevant for the book itself, but also for the author's own illness experience.

Although Kalinithi was a professional neurosurgeon, he also held academic degrees in English literature, which may help explain the high literary quality of his work. In the article 'The Writer as a Patient with a Brain Tumour: A Comparative Study', Soledad Pereyra discusses two works written by professional authors, both of whom were diagnosed with brain cancer. In her analysis and comparison of the autobiographical novels *A Journey Round My Skull* by Frigyes Karinthy and *Until Further Notice, I Am Alive* by Tom Lubbock, Pereyra shows how the authors' identity as intellectual, professional writers affects their work, yet at the same time, their medical condition affects how they identify themselves as writers. Moreover, with this particular diagnosis having an impact on the writers' cognitive capacities, the authors find themselves struggling precisely as writers in the writing process, which consequently affects their self-image as professional authors. They thus experience a divide between their previous existence and image as authors and their new image as cancer patients.

Katarina Bernhardsson also discusses two professional authors and how they deal with a cancer diagnosis in her article "The patient as reader: The uses of intertexts in two Swedish pathographies". Bernhardsson analyses how Swedish authors Anders Paulrud and Agneta Klingspor make use of other authors both in their own literary works, respectively *Fjärilen i min hjärna* (The Butterfly in my Brain) and *Stängt pga hälsosjäl* (Closed for Health Reasons) and in the way in which they handle their illness experiences, as described in their literary works. Bernhardsson illustrates in her article, how the authors use other texts in their own compositions and how reading other authors helps them in their everyday lives with cancer. Whereas Paulrud consciously makes intertextual references to other writers in his book, Klingspor initially completely resists relating to literature but eventually turns back to books and finds solace in reading. Bernhardsson demonstrates, how these two writers emphasise the concrete and everyday above the more symbolic and immaterial both in their books and in their situation of being

ill with cancer. Moreover, she shows how literature may have had a healing effect on Paulrud and Klingspor, and how it helped them convey their illness experience in their works of art.

Like Pereyra and Bernhardsson, Linda Nesby continues along the line of discussing professional authors' illness stories in her article "Together in Sickness", but she also addresses illness stories written by non-professionals. But whereas Bernhardsson focuses on her authors' relation to other writers, Nesby's focus is on that of the relative, and the role relatives play in narratives about illness. In her analysis, she applies literary scholar Roland Barthes' notion of "idiorrhythmy" as presented in his work *Comment vivre ensemble: Simulations romanesques de quelques espaces quotidiens* (How to Live Together: Novelistic Simulations of Some Everyday Spaces). Barthes employs the concept, originally used about the monastic and hermit lifestyle of the early Christian church, to the way in which modern people live their lives in different rhythms, yet they are nevertheless able to find ways of living together while simultaneously preserving their own rhythm. Nesby discusses four Scandinavian novels about patients diagnosed with cancer. The novels describe young and older adults suffering from cancer and staying at home and the challenges and strategies involved in living together or alone while experiencing severe illness. In her analysis, she adopts the concept of "idiorrhythmy" and explores the role of family members and the challenges one may encounter when living together or in a close relationship with someone experiencing severe illness. Nesby's article stresses the striving for both integrity and belonging and the vital question, then, is whether - and if so - how, the ill and the healthy people are able to adjust to one another. Whereas the institution and transcendental beliefs form the basis for the first two sections of this journal, in this third section the patient appears to be acting primarily as the sole subject. However, Nesby demonstrates in her article how subjectivity corresponds with and sometimes even confronts the social setting of which the patient nevertheless is unavoidably apart

In the last two articles that make up the fourth section of this special issue, the social setting is also in the forefront, but we have now moved into the social media context. Christian Lenemark and Carsten Stage present patient stories from the digital universe in their respective articles. First, Lenemark explores the way in which experiences of cancer are presented in three cases in the digital media in his article "Doing Illness. Cancer Narratives in Digital Media". Lenemark examines the blog *My body* by the Swedish journalist Kristian Gidlund, which was written during a period in which Gidlund suffered from aggressive stomach cancer. The blog was later published in book format. The next case explored by Lenemark,

is the Italian artist Salvatore Iaconesi's website *La Cura*, a project in which Iaconesi deals with his own brain cancer diagnosis online in an attempt to find a cure for his disease artistically. Iaconesi's project consists of several digital sources such as a website, social media and YouTube videos, and unlike Gidlund, he explicitly invites his readers/viewers to interact with him in his project. Consequently, his digital illness story becomes highly different from Gidlund's, as the latter consciously chose not to interact with his blog readers despite the fact that the readers actively commented on his blog. The third case discussed by Lenemark, is the video game *That Dragon, Cancer*, created by Ryan and Amy Green following the passing away of their five-year-old son Joel. According to Lenemark, the couple "*describe creating the game to commemorate Joel, and to raise awareness of what it means to care for a deathly ill child*". In exploring three such widely different cases, Lenemark demonstrates the variety of ways in which digital media enable new and innovative storytelling and ways of sharing illness experiences.

Carsten Stage delves more deeply into the social media universe in his exploration of the Danish cancer patient Janne's Instagram profile. By applying a 'small stories' approach to the cancer narrative as told through Instagram, Stage demonstrates how social media represent new ways of storytelling that are highly interactive. He explores the way in which Janne's Instagram followers interact and take part in the illness story by commenting on and 'liking' the patient's posts. In this way, the followers are not only witnessing the illness story as it progresses like a regular audience or readership; they actively take part in the story "*as crucial contributors to the social interaction and co-creation of desired narratives, subject positions, narrative progress and tellability*." Thus, Janne, despite being the owner of the Instagram account, is not fully in control of the small stories she presents nor ultimately of the overall larger story, as she comes to respond to her followers' comments and expectations, and moderates her own story in line with these. Together, Lenemark and Stage demonstrate how new ways of mediating stories affect storytelling and narrative techniques.

We sincerely hope that the contributions in this special issue on patient texts will provide food for thought on living with illness, either as a patient or a relative, on patient care and empathy, on the important aspects of life with or without illness and on what matters and what may be less significant in the larger picture.

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## Notes

- 1 See Hambro's contribution for a more elaborate discussion of the term.
- 2 For a discussion on pathography as genre, see Nesby (2019) "*Patografien som genre og funksjon*".