Patienten som tekst

Tidsskrift for Forskning i Sygdom og Samfund

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Aims and scopes

The Journal for Research in Sickness and Society is an interdisciplinary journal which has a theoretical background in medical anthropology. The aim and purpose of the journal is to promote and develop research in the borderland between the health sciences and the humanities/the social sciences. The goal of the journal is to function as a forum in which these disciplines may meet and inspire each other – epistemologically, methodologically and theoretically. The journal conveys the debate and theoretical development which takes place in the growing collaboration and research initiatives emerging from this borderland. The journal addresses all with an interest in research in sickness and society and especially health professionals working with education and/or research in interdisciplinary institutions.

Indhold

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Introduktion

Text and Context

The Patient as Text - Revisited

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As a tribute to the Norwegian literary scholar Petter Aaslestad's T*he 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 Retterstøl'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 Vidkunn 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*.[1] 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.[2] 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 pathographes 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 unprestigous 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 broader 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). Wesson 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 Hambro 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 demonstrates 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.

References

Aarseth, G., Natvig, B., Engebretsen, E., & Lie, A. K. (2017). 'Working is out of the question': a qualitative text analysis of medical certificates of disability. *BMC Family Practice,* 18(1), 55. https://doi.org/10.1186/s12875-017-0627-z

Aarseth, G. A. (2019). *The Language of Work Disability. A Study of Medical Certificates Written by Norwegian General Practitioners.* Ph.d. dissemination. Oslo: University of Oslo.

Aaslestad, P. (1997). *Pasienten som tekst. Fortellerrollen i psykiatriske journaler*: Gaustad 1890-1990. Oslo: Tano Aschehoug.

Alber, J., et al. (2010). Unnatural Narratives, Unnatural Narratology: Beyond Mimetic Models. *Narrative, 18(2),* 113-136. https://doi.org/10.1353/nar.0.0042

Bamberg, M. (2006). Stories: Big or small. Why do we care? *Narrative Inquiry, 16(1),* 139-147 https://doi.org/10.1075/ni.16.1.18bam

Bruner, J., 2004. Life as Narrative. *Social Research, 71(3),* pp. 691-710.

Federhofer, Marie-Theres, F., 2018. »I face a dark future.« *Letters from the Leprosy Archives,* Bergen. , 7, pp. 17-33. https://doi.org/10.5463/ejlw.7.232

Fehr, D. (2008). *Når kroppen tenker.* Oslo: Universitetsforlaget.

Felski, R. (2009). *Uses of literature* (Blackwell manifestos). Hoboken: John Wiley & Sons. https://doi.org/10.1002/9781444302790

Frich, J. (2006). Litteratur og medisin. *Tidsskrift for Den norske legeforening, 125(24*), 3406.

Frich, J. C. (2010). *Sykdom - nettverk av betydning.* Bøygen. Organ for nordisk språk og litteratur. Oslo: Universitetet i Oslo, 229-232.

Gamson, J. (2001). Celebrity. *International Encyclopedia of the Social and Behavioral Sciences,* pp. 1578-1581. https://doi.org/10.1016/B0-08-043076-7/04317-5

Gerhardt, M. (2016). *Der bor Hollywoodstjerner på vejen*, Copenhagen: People's Press.

Gygax, F. (2013). On Being Ill (in Britain and the US): Illness Narratives of the Self. *European Journal of Life Writing* [Online], 2:0. https://doi.org/10.5463/ejlw.2.42

Hawkins, A. H. *Reconstructing Illness. Studies in Pathography.* 2nd ed., Purdue University Press, 1999.

Lerner, B. H. (2006). *When illness goes public: Celebrity patients and how we look at medicine.* Baltimore: Johns Hopkins University Press.

Nesby, L., & Salamonsen, A. (2016). Youth blogging and serious illness. *Medical Humanities, 42(1),* 46-51. https://doi.org/10.1136/medhum-2015-010723

Nesby, L. H. (2019). Patografien som genre og funksjon. *Edda, 106(01),* 54-68. https://doi.org/10.18261/issn.1500-1989-2019-01-05

Ngai, S. (2005). *Ugly Feelings.* Cambridge: Harvard University Press. https://doi.org/10.4159/9780674041523

Økland, I. (2019). Moren undergraver Greta Thunberg. Book review. *Aftenposten 14 June 2019.* Read 17 June 2019.

Podnieks, E. (2009). Celebrity Bio Blogs: Hagiography, Pathography, and Perez Hilton. *Auto/Biography Studies 24(1)*: 53-73. https://doi.org/10.1080/08989575.2009.10846788

Retterstøl, N. (2006). S*tore tanker, urolige sinn: 21 psykiatriske portretter.* Oslo: Damm.

Rimmon-Kenan, S. (2006). What Can Narrative Theory Learn from Illness Narratives? *Literature and Medicine, 25(2),* 241-254. https://doi.org/10.1353/lm.2007.0019

Stene-Johansen, K., & Tygstrup, F. (2010). *Illness in Context.* Leiden: Brill. https://doi.org/10.1163/9789042029446

Tjora, A., & Sandaunet, A. G. (Eds.). 2010. *Digitale pasienter*. Oslo: Gyldendal akademisk.

Walter, T. (2010). Jade and the journalists: Media coverage of a young British celebrity dying of cancer. *Social Science & Medicine, 71(5)*, 853-860. https://doi.org/10.1016/j.socscimed.2010.06.003

Wasson, S. (2018). Before narrative: Episodic reading and representations of chronic pain. *Medical Humanities, 44(2)*, 106-112. https://doi.org/10.1136/medhum-2017-011223

Woods, A. (2011). The Limits of Narrative: Provocations for the Medical Humanities. *Medical Humanities, 37(2)*, 73-78. https://doi.org/10.1136/medhum-2011-010045

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*".

Originalartikel

Pain and epiphany:

Julian of Norwich' revelations of divine love *as pathography*

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This article discusses the medieval English mystic Julian of Norwich's autobiographical text Revelations of Divine Love and the significance of physical pain in Julian's holy visions. Applying Anne H. Hawkins' idea of the 'myth of rebirth', the article argues that although Julian's work is not a narrative about illness as such, it may nevertheless be read as a medieval pathography or as a representative for a pre-stage genre of the modern pathography. Moreover, by applying theories on the phenomenology of pain, it discusses whether we may learn something today from the way in which medieval religious writers found a theological meaning in pain and whether painful experiences may help develop positive character traits.

In 1373, Julian of Norwich received a series of sixteen holy visions during a serious illness from which she was expected to die. Instead, she miraculously recovered from her illness and wrote down her visions in what has become known as her *Revelations of Divine Love* or *Shewings* (modern English 'showings'). Julian's writings are known to be the first literature written in English by a woman. But her writings are much more than that: *Revelations of Divine Love* is also a medieval illness story, an account of a near-death experience, an account of sixteen holy visions – some of which manifested themselves in intense physical pain – and it is an account of Julian's highly developed theology of love, for which she is best known.

Finally, it is an account of how Julian, in line with medieval religious ideas, found meaning in pain and suffering and how her religious epiphany led to personal growth and spiritual wellbeing.

In this article, I explore whether theology and medieval studies may contribute to the field of medical humanities by examining descriptions of holy pain in Julian of Norwich's *Revelations of Divine Love.* More specifically, this article is a contribution to the study of pathographies, and I argue that the genre may be traced back at least as far as the Middle Ages. I discuss whether Julian's work may be read as an early pathography despite the fact that Julian hardly describes her own illness at all in her autobiographical account. She does, however, describe the intense somatic pain she experiences in her visions, although she does not relate this pain to her actual illness *per se.* In line with medieval religious ideals, moreover, Julian finds meaning in this pain, which becomes instrumental for her spiritual development and wellbeing. With Julian's epiphanic experiences in mind, I will discuss whether we might learn something today from medieval attitudes to pain as a means for personal growth. In doing so, I provide a phenomenological approach to the topic under discussion and apply theories on the phenomenology of pain articulated by scholars such as Drew Leder, Espen Dahl and Ariel Glucklich.

What is a pathography, really?

There are numerous definitions of the term *pathography*, ranging from the definitions that include more or less anything you want to be included to the more stringent, narrow interpretations of the term. The Merriam-Webster online dictionary gives the following, broad description: *"biography that focuses on a person's illnesses, misfortunes, or failures; also: sensational or morbid biography"* (https://www.merriam-webster.com/dictionary/pathography). Literary scholar Anne H. Hawkins, on the other hand, suggests a more exclusive definition, emphasising the personal experience and the illness as key factors: *"a form of autobiography or biography that describes personal experiences of illness, treatment, and sometimes death"* (Hawkins 1999:1).

If we dissect the compound *pathography*, the first part of the Greek term is Πάθος (pathos), meaning 'emotion', 'passion'. The meaning of the Latin *passio* furthermore, a translation from the Greek Πάθος, is 'illness', 'suffering' or 'martyrdom'; the term is best known to us with reference to the passion story in the New Testament. The Latin verb *patior*, moreover, means 'to suffer' or 'to endure'. Based on these meanings, we may broadly define pathography as written texts (γραφή, 'graphē') about strong emotions, passion, illness or suffering, and even martyrdom, with the biblical accounts of Christ's passion as the literary climax of the latter. Hawkins moreover focuses on the *transition* brought about by the passion, illness or suffering in the life of the affected, emphasising that

> "*[p]athographies are compelling because they describe dramatic human experience of real crisis: they appeal to us because they give shape to our deepest hopes and fears about such crises, and in so doing, they often draw upon profound archetypal dimensions of human experience. If this is so, one might wonder why it is that pathographies were not more in evidence in previous eras and cultures*" (1999:31).

She goes on to argue that these stories do in fact exist in previous eras and cultures, but in a different form (or should we say forms?), and that the modern pathographies' closest counterpart are autobiographies that describe religious conversion (Hawkins 1999:31). One of the striking similarities between the modern pathography and the older conversion narrative is that they both "*give special prominence to myths about personal change*" (33). In her treatment of conversion stories from seventeenth-century England, Hawkins notes that there are very few accounts of actual illness, but in those that do exist, the illness is treated as "*a means for spiritual growth*", and the physical dimension of the illness is interpreted as "*a metaphor for the spiritual*" (31). Thus physical recovery and wellbeing equal spiritual growth and wellbeing, underlining Hawkins' emphasis on change in the life of the experiencer. This is in line with the pre-Cartesian world-view, which lacks the modern, post-Cartesian, dichotomy between body and soul, representing a more holistic view of physical and mental wellbeing as interconnected and co-dependent (McKinstry and Saunders 2017: 141-142, Saunders and Fernyhough 2016, Saunders 2016:412). I concur with Hawkins in this claim. She goes on to demonstrate how narratives concerning such personal transformation with emphasis on the spiritual and the religious – described by Hawkins as precursors to the pathography – go much further back in time than Hawkins' own treatment of the phenomenon in seventeenth-century England. In fact, considering the examination of the term pathography above, we may at least go as far back as Jesus Christ and further (as shown by Hawkins). By way of example, the gospel narratives' descriptions of Christ's passion provide biographical accounts of experiences of suffering, pain and death, in line with Hawkins' definition above. Moreover, although the term 'martyr' (Gr. Μάρτυς) is also used in the secular sphere, I believe it is safe to say that the passion narrative is the most famous *passio* in the martyrdom sense of the term. In further accordance with Hawkins, the story of Christ's passion is doubtlessly a description of a "*dramatic, human experience of real crisis*", which may perhaps partly explain why the Bible still has such an appeal. At least, in her own discussion of pathographies, this is one of Hawkins' explanations to why these illness stories fascinate so many readers. Moreover, in line with Hawkins description, the biblical account of the resurrection, following the passion narrative, has for centuries or even millennia been "*giving shape to our deepest hopes (…) about such crises.*" It is precisely the passion narrative, describing an extreme, but nevertheless meaningful pain, that brings about personal change in Christ's followers. This, we shall see, is also the case with Julian of Norwich. Thus, although it may be argued that his pains do not bring about personal change in Christ himself, his meaningful suffering for the love of humankind has an epiphanic and transformable effect on his followers.

Hawkins also notes with regard to the connection between seventeenth-century conversion narratives and the modern pathography that " *[i]t almost seems as though pathography has replaced the conversion autobiography of earlier, more religious cultures*" (Hawkins 1999:31). This replacement of the religious conversion narrative in the seventeenth century with the illness story of today demonstrates a move from religious to secular society, from trust in God to trust in medical science and from finding relief and wellbeing in the faith in God to laying our lives in the hands of science and medical doctors. Yet at the same time, recent research shows that patients of today also seek out more spiritual treatments such as healing, not necessarily to replace conventional medicine, but as a supplement in their need for a more holistic treatment than what they find offered in the conventional medical institutions (Larsen 2018, Kiil & Salamonsen 2013, Kiil 2019). That conventional medical treatment is not always enough for the ill patient and/or relatives, who wish to be seen as more than a diagnosis or a body part, is also indicated from the subgenre of the modern pathography termed 'angry pathographies' by Hawkins: "*Recent pathographies demonstrate our cultural discontent with traditional medicine in two different ways: by the expression of anger at callous or needlessly depersonalizing medical treatment and by a concern with alternative therapies*" (Hawkins 1999:5).

The Norwegian professor of psychology Ole Jacob Madsen has noted that in today's society, the clergy has been replaced by the psychologist, whom he terms 'the new clergy', as carers for human mental and spiritual wellbeing, in a shift from focus on salvation (with emphasis on the afterlife) to health (with emphasis on this life) (http://www.verdidebatt.no/innlegg/11685197-de-nye-prestene, Madsen 2017b). The similarity that Hawkins sees in the modern pathography and in the older conversion narrative is what she describes as the 'myth of rebirth' also referred to as 'the regeneration paradigm'. This myth or paradigm is characterised by *"the belief that it is possible to undergo a process of transformation so profound as to be experienced as a kind of death to the 'old self' and rebirth to a new and very different self"* (Hawkins 1990:547). A common feature is the death to an old troubled or sick self and the birth of a new, healthy or enlightened self, that is, physical and mental wellbeing through pathos/passio. This description is in line with Julian of Norwich's experiences as recounted in her autobiographical writings, to which I will now turn.

Julian of Norwich: her life, her works and her religious experiences

Hardly any information exists about Julian of Norwich apart from what she provides herself in her own writings.[1] We don't even know her real name. But through her own account, we know that she was an English mystical writer (c.1343-c.1416) who by the age of thirty experienced a series of sixteen holy visions while lying seriously ill in 1373 (Windeatt 2016:xiii). Although she, her family and companions expected her to die from her illness, she nevertheless recovered and in the aftermath, she wrote down her experiences in the texts now known as the *Revelations of Divine Love* or simply *Shewings*. These texts are the first pieces of literature known to ever have been written in the English language by a woman, and considering that Julian describes herself as 'ignorant' and 'unlettered', and the fact that women were normally not given any proper education in England at the time (Windeatt 2016:xv, Novotny 2015:1), they are of remarkably high literary quality. Following her illness, Julian became an anchoress connected to the Church of St. Julian (from whence we have her name) in Norwich, and she flourished there as a religious councillor for people who came to seek her spiritual guidance until her death in c. 1416. Julian's *Shewings* exist in two versions – the short text and the long text – written with a gap of approximately twenty years, according to her own estimation. In the more or less immediate aftermath of her illness, she first wrote down her experiences in what is known as the short text, divided into twenty-five short chapters. She then meditated and reflected upon her visions for another twenty years before she wrote her long text of eighty-six chapters, consisting of a longer account of her visions but also of her own well developed theology. In essence, Julian's theology, which is based upon her mystical experiences, teaches that God is all wisdom and all love and all power, and that therefore, in the end, all shall be well (cf. ch. 27: *"all will be well, and all will be well, and every kind of thing will be well"*).

Her visions have been known as a literary work to the public since a version of the long text in modernised language was first published in 1670 by the English Benedictine Serenus Cressy. Only one copy of the short text has survived, found among other shorter spiritual works in the MS British Museum Add. 37790, also called the 'Amherst' manuscript after its last private owner. The handwriting of the manuscript has been dated to c. 1450. The British Museum bought the unique manuscript of the short text in 1900, after it had been passed from the hands of one private owner to the other since the Dissolution of the Monasteries in the 1530s and 40s (Colledge and Walsh 1978:17). Only one surviving manuscript witness of the long text predates the Dissolution of the Monasteries in the sixteenth century. This manuscript has been dated to c. 1500. The manuscript now considered the most important witness is the MS Fonds anglais 40 from c. 1650, preserved in the Bibliotèque Nationale in Paris (Colledge and Walsh 1978:21).

Before turning to Julian's visions, let us have a look at what characterises medieval vision literature and mysticism. Vision literature, that is accounts of holy visions, make up a large corpus within medieval devotional writing. These accounts can be fictional, semi-fictional, biographical or autobiographical. Autobiographical descriptions of holy visions, revelations or religious experiences are often referred to as mystical, forming the textual basis of what in modern times has been termed mysticism. Definitions of mysticism abound and cannot be discussed at length here, but one of the most authoritative researchers on the topic is Theologian Bernard McGinn, who defines 'mysticism' as *"a special consciousness of the presence of God that by definition exceeds description and results in a transformation of the subject who receives it"* (1998:26). Medievalist and Religious Historian Barbara Newman (2013:41) provides a much wider definition: *"a quest for experiential union with God."* It is uncontroversial to say that medieval mystics, or visionaries[2], experienced what they perceived as one or several encounters with the divine. These encounters were of a highly spiritual character, yet they often involved intense physical pain, which is often also referred to as 'sweet' or joyful.

Whereas McGinn in the above definition emphasises the experience of divine presence and the experiencer's personal epiphanic transformation, Newman underlines the quest for divine union. All these aspects are in play in Julian's mystical experience: In her quest for experiential divine union, she receives visions in which she experiences a divine presence. As a result, she undergoes a personal transformation and comes to know herself and God in new ways. Herein lies her epiphany. This is in line, as far as I can see, with Hawkins' description of conversion narratives from the seventeenth century and her 'myth of rebirth', and supports my argument that this myth may be drawn further back in time than Hawkins' treatment of seventeenth-century conversion literature.

Julian's illness

Julian's illness is the vessel through which she experiences her visions, and her autobiographical text is one of few first-person accounts of pain and illness by a woman from the Middle Ages. According to Medieval Historian Esther Cohen, no women left as graphic descriptions of pain and illness as some men did, and although *"there is no lack of self-descriptive women's writings, the voice of the ill woman is silent on the whole"* (Cohen 2003:207). Neither is Julian particularly communicative in terms of describing her illness as such. Whereas she describes and elaborates on the pains she experiences in her visions, the only information she shares with her readers about her own illness – which was so severe that she was close to death and thus presumably also painful for her – is that her body felt *"dead from the middle downwards"*, then that the upper part of her body began to die, and that *"the greatest pain that I felt was my shortness of breath and the ebbing of my life"* (Short text, chapter 2, p. 128). Disappointingly, perhaps, this is all the information we get from one of the few first-hand accounts we have in literary history of what seems to have been a near-death experience. Although we can deduce little information about her illness, however, her account of her visions are all the more elaborate and provide invaluable information about her mystical experiences.

Julian's five desires and her experiences of ecstatic pain

In the opening chapters of both the short and the long text, we learn that Julian prayed to God for the gift of a bodily illness so serious that she would be close to death, and

> *"[i]n this sickness I wanted to have every kind of pain, bodily and spiritual, which I should have if I were dying (…) and every other kind of pain except the departure of the spirit, for I hoped that this would be profitable to me when I should die (…)"* (Short text, chapter 1, p. 126).

She goes on to describe five desires that she prayed God to fulfil, all being described in terms of pain. The first desire was 1) to experience a serious illness, the second 2) to experience the pains of Christ's suffering, and next that she would receive three 'wounds' from God: 3) the wound of contrition, 4) the wound of compassion, and 5) the wound of *"longing with all my will for God"* (Short text, chapter 1, p. 127). That Julian's desires are five in number and described in terms of pain (illness, suffering, wounds) is not coincidental. They reflect the medieval devotion to the five holy wounds of Christ and the belief in their healing powers as stated in 1 Peter 2:24: *"By His wounds you were healed"*.

Julian's first desire is fulfilled with her illness; the second when she receives her sixteen holy visions wherein she experiences the pains of Christ's suffering on her own body. It is in her visions that she receives the recollection of Christ's Passion and her third desire, the 'three wounds' of contrition, compassion and longing for God.' These wounds lead to her epiphanic awakening and her union with God, and she thus considers the illness a gift from God through which she received her visions and ultimately her personal transformation.

In her visions, Julian sees a *"supreme spiritual delight"* free from pain before everything changes. She then feels abandoned and such despair that she *"hardly had the patience to go on living"* (Long text, chapter 15, p. 204). These two opposite feelings alternate over and over again in the vision:

> *"And then again I felt the pain, and then afterwards the delight and the joy, now the one and now the other, again and again, I suppose about twenty times."* (Long text, chapter 15, p. 205)

She then has a vision of the Crucifixion of Christ, which she experiences as immensely painful:

> *"[t]his revelation of Christ's pains filled me full of pains, (…). And in all this time that Christ was present to me, I felt no pain except for Christ's pains; and then it came to me that I had little known what pain it was that I had asked, and like a wretch I regretted it, thinking that if I had known what it had been, I should*

> *have been reluctant to ask for it. For it seemed to me that my pains exceeded any mortal death. I thought: Is there any pain in hell like this pain? And in my reason I was answered: Hell is a different pain, for in it there is despair. But of all the pains that lead to salvation, this is the greatest, to see the lover suffer."* (Long text, chapter 17, p. 209)

There is a paradox in Julian's description that is not uncommon in medieval accounts of mystical experiences: On the one hand, Julian describes what we typically refer to as an out-of-the-body or ecstatic experience that is highly spiritual, yet on the other hand, she describes it as physically painful. Moreover, the pain she experiences in her visions is a pain that she has prayed for and that she welcomes. This feeling of positive affect in relation to holy pain is reflected in various other mystical writers from the middle ages and the early modern period. Julian's contemporary, the English mystic Richard Rolle describes in his work *Incendium Amoris* ('The Fire of Love') a similar experience:

> *"I was more astonished than I can put into words when, for the first time, I felt my heart glow hot and burn. I experienced the burning not in my imagination but in reality, as if it were being done by a physical fire. I was really amazed by the way the burning heat boiled up in my soul and (because I had never before experienced this abundance), by the unprecedented comfort it brought. In fact, I frequently felt my chest to see if this burning might have some external cause."* (Rolle 1981:93)

One of the best known such experiences of holy pain is found in the writings of the Spanish sixteenth-century mystic Teresa of Avila, who, like Rolle, describes the pain both in terms of burning flames in the heart and as a sweet pain:

> *"I saw an angel close by me, on my left side, in bodily form. This I am not accustomed to see, unless very rarely. (...) I saw in his hand a long spear of gold, and at the iron's point there seemed to be a little fire. He appeared to me to be thrusting it at times into my heart, and to pierce my very entrails; when he drew it out, he seemed to draw them out also, and to leave me all on fire with a great love of God. The pain was so great, that it made me moan; and yet so surpassing was the sweetness of this excessive pain, that I could not wish to be rid of it. The soul is satisfied now with nothing less than God. The pain is not bodily, but spiritual;*

> *though the body has its share in it, even a large one.*" (http://www.gutenberg.org/files/8120/8120-h/8120-h.htm#l29.0, Ch. XXIX, 16-17)

How should we explain these two paradoxes between the spiritual and the physical on the one hand, and the painful and the joyful on the other? And how are these tensions relevant to Julian's religious healing? I suggest that the key notion in explaining these tensions lies in the medieval ideal of *Imitatio Christi* through bodily pain.

Late medieval culture of pain and the ideal of *Imitatio Christi*

In the European later Middle Ages, pain and suffering were central themes, among theologians, physicists and legal scholars alike as well as in monastic circles and among the laity (Cohen 2010, 2003). But why this focus on pain and suffering? Pain was, of course, an ever-present part of medieval society, with plagues, various wars, low life expectancy, few medical cures for diseases and so on, but there is little evidence to suggest that the later Middle Ages were more painful than earlier times (Cohen 2010:3). Yet the focus on pain and suffering seems to have escalated precisely in this period. This focus seems to go hand in hand with increased attention to the suffering Christ. In the later Middle Ages, the Christian world-views reflected in both scholasticism and monasticism saturated Christian European societies. Scholasticism saw its peak in the later Middle Ages, while new monastic orders were established across Europe simultaneously. The religious focus was on the Crucifixion and the Passion of Christ, and consequently, the holy was largely connected to pain. Because suffering was seen as such a central part of human and salvation history, with Christ's passion as its zenith, this focus on pain is perhaps not so surprising after all. What further characterises this central theme in the later medieval period, however, is a new emphasis on the positive aspects of pain that we see, for instance, in medieval mysticism. Mystical writers drew attention to the usefulness of pain and to how pain might function as a way to perfect the soul. Pain and suffering were in some cases seen as a gift from God, as reflected in Julian's five desires. In a culture where everything in this life could be considered to affect the next, pain was regarded as a meaningful preparation for the afterlife and as a way to reduce suffering on the other side. Ultimately, the meaning of pain was to understand Christ's sufferings. Christ had suffered and died for humankind, and human salvation was founded on his pain. The ideal way to perfect one's own soul in preparation for the afterlife was to attempt to fully comprehend this through imitating His pain – *imitatio Christi*. The idea was to seek identification with Christ through suffering, to experience His pains as far as possible, although the mystics acknowledged that He had suffered more than any other human being for the entire human race. This is what we see reflected in Julian's desire to experience Christ's suffering, and in her visions of the passion in which she takes share in his pain. Theologian Frederick Bauerschmidt has noted that

> *"[i]t is only when Julian actually becomes sick that she seems explicitly to connect her second request [to experience Christ's passion] to the first [a severe illness], so that the pain of her bodily sickness becomes part of her identification with Christ. […] Her desired sickness is not simply purgative; it is […] a form of imitation"* (Bauerschmidt 2008:39).

In line with the ideal of *Imitatio Christi*, the way to God is through pain. However, as Christ suffers with joy because of his love for humankind, in a similar manner the mystics also found joy in their pain, since they suffered for their love of Christ, and the pain they experienced was considered a means for getting closer to the divine. Herein lies yet another meaningful aspect of the pain. But the main emphasis is on how identification with Christ through pain enables the perfection of the soul and leads to spiritual development. Julian recovers from her illness and her pain experiences as a new, transformed human being.

In today's western society, there seem to be a tendency to use all means necessary in order to avoid pain. We take a painkiller if we have a headache or we see the doctor when we feel pain that can not immediately be explained as something natural that will soon pass in and of itself. Theologian and phenomenologist Espen Dahl describes pain as an 'evil', and as *"something that should not be"*, although he acknowledges that there are certain gains that may come through pain, such as *"the pain of growth, pain as signals of danger, and* gains that can only come through pain" (Dahl 2017, 396, my emphasis). In theological discussions on theodicy, that is, the question of why an almighty, omniscient and good God permits evil to happen, theologians such as John Hick (2010) and Richard Swinburne (1998) both argue that evil is a necessary ill that promotes the development of favourable human character traits such as love, empathy, truthfulness and courage. I will argue that the medieval religious idea of illness and pain as gifts from God may be read today as a metaphor for something similar. In Western secular society, thoughts about perfecting the soul in preparation for the afterlife may seem dated to many of us and of little relevance today. Yet in line with Hick's and Swinburne's ideas of evil as a necessary ill for developing positive character traits, is it possible to consider pain not only as an evil but also as a meaningful human experience that may promote the same kinds of favourable traits?

The medical doctor and phenomenologist Drew Leder has pointed out how we tend to forget our body when it works normally. We don't think about our body when we breathe normally, walk, drive, cook or conduct other everyday activities that involve the use of our body. Leder terms this 'the absent body' (Leder 1990:69). When we experience pain, however, we become immediately aware of our body and we suddenly focus on the body that had hitherto been 'absent'. As Dahl has noted in this connection, when we experience physical pain, we no longer *have* a body, we *become* our body (Dahl 2015:153). He further argues that "*pain is the human experience that to the highest extent manifests human embodiment*" and that therefore, nothing makes us more self-conscious than when we experience bodily pain (Dahl 2015:151). I suggest that the notion of pain as an evil that should not be represents a relatively modern western idea and a modern, western focus on physical wellbeing free from pain precisely because pain is considered an unnecessary evil. In the mystical visions from the Middle Ages, however, this idea of pain as "*something that should not be*" is not recognised, because although the pain experienced in the visions is extreme, it is also described in terms of positive affect and considered meaningful. The experiencers welcome the pain, they have prayed for it and don't want it to go away.

Through the physical pain experienced in the visions of Christ's passion and the identification with Christ, I argue that it becomes impossible for Julian to forget the body and the pain, since, in accordance with the phenomenology of the body outlined above, the bodily presence is at its most intense when we experience pain. Although, the pain offers an intense here-and-now experience, the joy related to the identification with Christ paradoxically offers an ecstasy[3] that involves a *loss of self* or an out-of-the-body experience. The mystical experience thus becomes both intensely physical and ecstatic at the same time. The physical comes to represent the pain, and the spiritual, or ecstatic, to represent the joy of union with the divine, which, paradoxically, derives from the painful imitation of the Passion. Julian's ultimate religious healing or transformation lies in her realisation upon which her theology rests, the epiphany that all things shall be well because God is all love and all power. It is significant that Julian's desire for suffering is not for the pain in and of itself but because experiencing this holy pain is a way of focusing her attention on God, which will ultimately lead to her own religious transformation or fulfilment. Bauerschmidt notes in this connection that ultimately, it is not Julian's mystical experiences or the pain or the illness in and of themselves that are of significance; "*what matters is the revelation that she is given – the message of the nature and scope of God's merciful love*" (Bauerschmidt 2008:46). It is what comes out of the pain experience that is meaningful. So what may we learn from Julian's experiences today? Dahl's notion above, that there are certain gains that can only come through pain, is essential here, as Julian sees pain as a means to achieve a higher goal. We immediately consider pain an evil, something that should not be, says Dahl. This implies that we rid ourselves with a fundamental human experience, and we may ask ourselves if something would be lost to us if the experience of pain disappeared altogether. But to the medieval mystics, pain was something that definitely *should* be. Although Dahl recognises that there may be gains that can come through pain, he fails to address a deeper, positive meaning that was so central to the medieval mystics. And although the theological significance of pain that was acknowledged and appreciated in the later Middle Ages may seem distant to us today, I argue that there may be ways of appreciating meanings of pain or meanings that may come from pain also today. Giving birth would seem to be the ultimate example of such meaningful pain, and birth-giving may also serve as a metaphor for Julian's experiences: although the illness and the suffering itself may not be meaningful *per se*, the pain *gives birth* to meaning by way of her participation in the passion of Christ. Although Julian is not resurrected as such, she comes out of her near-death experience as a transformed human being transformed as a result of her participation in *Christ's* death experience. Thus, the pain experience also gives birth to the newly awakened and transformed Julian.

Conclusions

May mystical literature of holy visions be included in the precursory genre of the pathography as suggested by Hawkins in her discussion of seventeenth-century conversion narratives? Whether we can regard Julian's autobiographical writings as a pathography or not depends on our definition of the genre, and how inclusive we are in our definition. The *Revelations of Divine Love* is certainly not a typical, conventional pathography, but I will nevertheless make a case for Julian's work as a medieval pathographic text or as representing a pre-stage to the modern pathography.

Julian is healed from her illness following a series of holy visions, some of which include intense physical pain. When Julian recovers and comes back from her near-death experience, she comes back as a fundamentally different person, as an 'other' Julian than the person who commenced the journey by praying for illness and suffering. When she comes out of her mystical experience, she perceives herself, her faith and the world in new ways. The illness that brought her to the verge of death may be read as a metaphorical death of Julian's old self, and her climax, her shared suffering with Christ in his death on the cross marks a rebirth of a new, transformed self. Herein lies her conversion narrative, comparable to the precursors of the pathography suggested by Hawkins.

Julian's visions mark the climax of her spiritual journey from a naïve, uneducated believing woman to a spiritually fulfilled mystic with a highly developed theology. Julian acquires mental and physical health and wellbeing through illness and suffering, and thus, concretely, Julian is healed of her illness through her visions, but her visions also offer spiritual healing, making Julian's soul whole and filled with love for God and compassion for her fellow humans. This compassion has a social aspect in her functioning after her recovery as a religious councillor for those who sought her spiritual guidance. Her own epiphany and transformation results in wisdom with which she reaches out to others in need of religious guidance. The new Julian thus takes on a role as a medieval therapist. She becomes the manifestation of the Nietzschean cliché 'what doesn't kill you makes you stronger' and her new strength is channelled into helping others in their spiritual search. This social aspect of Julian's religious wisdom can still be seen today in her great popularity among people both belonging to the Christian faith and to other religions, from both within academia and outside, from both among the Church and the laity. In Norwich today, Julian's church and shrine have been restored and has become an attractive destination for pilgrims. Her works and secondary literature on Julian and her visions are on sale in churches and bookshops across the western world. Her words are quoted frequently, and she is revered by the Anglican Church (Grange 2003:11). According to Physician John Grange, Julian has also played

> *"a key role in bringing silent contemplative meditation back into the English Christian tradition. There are, in Britain, around 400 ecumenical Julian Meet-*

> *ings – groups of people who meet regularly for contemplative meditation"* (Grange 2003:11).

Thus, Julian's own religious transformation has brought religious healing and wellbeing even to contemporary worshippers, and her message of love is as relevant today as it was in her own time. Through her works, she still heals today.

The *pathos* of Julian's autobiographical pathography is certainly present, both in her illness and in her experiences of Christ's *passion*. One may argue that given the focus on her religious experiences rather than on her illness, *Revelations of Divine Love* is not an illness narrative as such. This same argument goes for Hawkins' conversion narratives. Yet, although illness is a key factor in the modern pathography, I would argue that they, too, are about something fundamentally *more* than the actual illness experience. They, too, are often about the positive traits that may come from experiencing something as life-changing and epiphanic as serious illness may be, such as hope, personal growth, a realisation of life's realities, compassion and courage. We find such traits also expressed in the vocabulary of illness itself in the pathographies, whether they belong to the religious sphere of the Middle Ages, the sixteenth century or to the modern-day world of medicine. As Linda Nesby has noted, in the vocabulary of illness *"we find not only expressions of grief, pain and death, but also of hope, joy, courage and coping with life"*[4] (Nesby 2018 http://nordnorskdebatt.no/article/hvordan-skriver-vi-om-sykdom).

Notes

1 For details about the historicity of Julian and the transmission of her texts, see Windeatt's introduction to Julian of Norwich's *Revelations of Divine Love* (2016)

2 I use the two terms synonymously here

3 As in Greek ἔκστασις 'ekstasis', being a compound of 'ek', out of and 'stasis', state, position, standing, condition – suggests a definition along the lines of 'being set out of one's state or position', or, as Ariel Glucklich suggests, "standing outside oneself" or "in a state of trance" (Glucklich 2015:4)

4 I vokabularet for sykdom "ligger ikke bare uttrykk for sorg, smerte og død, men også for håp, glede, mot og livsmestring."

References

Bauerschmidt, F. (2008). Julian of Norwich and the Mystical Body Politic of Christ Studies in *Spirituality and Theology 5*, Notre Dame, Indiana: University of NotreDame Press.

Cohen, E. (2003). 'The Expression of Pain in the Later Middle Ages: Deliverance, Acceptance and Infamy'. In Egmond and Zwijnenberg (Eds.), *Bodily Extremities: Preoccupations with the Human Body in Early Modern European Culture* (pp. 195-219). Aldershot: Ashgate Publishing.

Cohen, E. (2010). *The Modulated Scream. Pain in Late Medieval Culture*. Chicago: University of Chicago Press. https://doi.org/10.7208/chicago/9780226112695.001.0001

Colledge, E. & Walsh, J. (1978). 'Introduction' in Julian of Norwich *Showings*, ed. and tr. Colledge and Walsh. New York: Paulist Press

Dahl, E. (2017). 'The inner tension of pain and the phenomenology of evil', in *International Journal of Philosophy and Theology, Vol. 78.(4-5)*, pp. 396-406 https://doi.org/10.1080/21692327.2017.1304231

Dahl, E. (2015). 'Inkarnasjon, kors og smertens fenomenologi, in *Teologisk Tidsskrift no. 2*, pp. 148-163

Glucklich, A. (2001). *Sacred Pain. Hurting the Body for the Sake of the Soul*. Oxford: Oxford University Press

Grange, J. (2003). 'Julian of Norwich - Her relevance to healing today' in *Sacred Space, vol. 4, Issue 4*, pp. 7-12 https://doi.org/10.1002/shi.188

Hawkins, A. H. (1990). 'A Change of Heart: The Paradigm of Regeneration in Medical and Religious Narrative', in *Perspectives in Biology and Medicine, Vol. 33, No. 4*, pp. 547-559 https://doi.org/10.1353/pbm.1990.0058

Hawkins, A. H. (1999). *Reconstructing Illness. Studies in Pathography*. Indiana: Purdue University Press. Second edition.

Hick, J. (2010). *Evil and the Love of God*. New York: Palgrave Macmillan. https://doi.org/10.1057/9780230283961

Julian of Norwich (1998). *Showings* (ed. and tr. Colledge and Walsh). New York: Paulist Press

Kiil, M. & Salamonsen, A. (2013). 'Embodied health practices: The use of Traditional Healing and Conventional Medicine in a North Norwegian Community', in *Academic Journal of Interdisciplinary Studies, Vol. 2, No. 3*, DOI: 10.5901/ajis.2013.v2n3p483

Kiil, M. (2019). *In Home we trust. An ethnographic study of mental health and the use of traditional medicine in a North Norwegian community*. PhD dissertation, UiT the Arctic University of Norway.

Larsen, A. L. (2018). *Mapping the experience and use of traditional healing in Northern Norway. Among conventional health care providers, users and traditional healers.* PhD thesis, UiT the Arctic University of Norway https://munin.uit.no/bitstream/handle/10037/12836/thesis.pdf?sequence=2&isAllowed=y

Leder, D. (1990). *The Absent Body. The University of Chicago Pres*s. Chicago/London, 1990.

Lewis & Short. *A Latin Dictionary*. (Search word: 'passio', 'patior', last downloaded 02.11.2018) http://www.perseus.tufts.edu/hopper/text?doc=Perseus%3Atext%3A1999.04.0059%3Aentry%3Dpassio http://www.perseus.tufts.edu/hopper/text?doc=Perseus%3Atext%3A1999.04.0059%3Aentry%3Dpatior

Liddell & Scott. *A Greek-English Lexicon*. (Search word: 'Πάθος', last downloaded 02.11.2018) http://www.perseus.tufts.edu/hopper/text?doc=Perseus%3Atext%3A1999.04.0057%3Aentry%3Dpa%2Fqos

Madsen, O. J. (2017a). 'De nye prestene' in *Vårt Land* (last downloaded 01.07.2019) http://www.verdidebatt.no/innlegg/11685197-de-nye-prestene

Madsen, O. J. (2017b). *Den terapeutiske kultur*. Oslo: Universitetsforlaget.

McGinn, B. (1998). *The Flowering of Mysticism. Vol. III of The Presence of God: A History of Western Christian Mysticism*. New York: The Crossroad Publishing Company.

McKinstry, J. & Saunders, C. (2017). 'Medievalism and the medical humanities', in *postmedieval: a journal of medieval cultural studies Vol. 8*, pp. 139-146. https://doi.org/10.1057/s41280-017-0052-4

Merriam-Webster's online dictionary (searchword: 'pathography', last downloaded 02.11.2018) *https://www.merriam-webster.com/dictionary/pathography*

Nesby, L. (2018). 'Hvordan skriver vi om sykdom?' in *Nordlys* (last downloaded 04.11.2018) https://nordnorskdebatt.no/article/hvordan-skriver-vi-om-sykdom

Newman, B. (2013). 'Gender'. In Lamm, J. A. (Ed.), *The Wiley-Blackwell Companion to Christian Mysticism* (pp. 41-55). Blackwell Publishing Ltd. https://doi.org/10.1002/9781118232736.ch3

Novotny, T. E, (2015). *Julian of Norwich: Voicing the Vernacular*. Dissertations (2009 -). Paper 524. http://epublications.marquette.edu/dissertations_mu/524

Rolle, R. (1981). 'The Fire of Love' in *The Fire of Love and the Mending of Life*, trans. M. L. del Mastro. New York: Image Books, pp. 93-264

Saunders, C. (2016). 'Voices and Visions: Mind, Body and Affect in Medieval Writing', in *The Edinburgh Companion to Critical Medical Humanitie*s, ed. Whitehead and Woods, Edinburgh University Press. Edinburgh, pp. 411-427.

Saunders C. & Fernyhough, C. (2016). 'The medieval mind' in *The Psychologist vol. 29*, pp. 800-803, https://thepsychologist.bps.org.uk/volume-29/november-2016/looking-back-medieval-mind (last downloaded 04.11.2018)

Swinburne, R. (1998). *Providence and the Problem of Evil*. Oxford: Clarendon Press. https://doi.org/10.1093/0198237987.001.0001

Teresa of Avila. *The Life of St. Teresa of Jesus.* Project Gutenberg's The Life of St. Teresa of Jesus, by Teresa of Avila (last downloaded 04.11.2018) http://www.gutenberg.org/files/8120/8120-h/8120-h.htm#l29.0

Windeatt, B. (2016). 'Introduction', in *Julian of Norwich. Revelations of Divine Love*. Edited by Barry Windeatt. Oxford: Oxford University Press, pp. xiii-lii

Originalartikel

Gothic Infections

Henry Tilney and Storytelling as Therapy

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This article proposes, a reading of Jane Austen's Northanger Abbey (1818) as a case study for discussing infectious literature, storytelling as therapy and the interconnectedness of Gothic methodologies and medical humanities. Northanger Abbey was written in a period when women's reading habits was a contested topic, so I will provide a quick historical overview of the period and the problematic Gothic novel, which Northanger Abbey satirizes. Where previous research has focused on Catherine Morland, the protagonist and 'misreader' in this Gothic satire, this article will focus on Austen's feminized hero, Henry Tilney, and read him in the role of a mesmeric healer. His goal is to cure Catherine of her obsession with Gothic novels, in order for her to fulfil the feminine ideal of the time. The mesmeric method is to produce a crisis in the patient, however, I will show how Henry's plan fails and he inadvertently produces a crisis in himself, and forces him to realize the extent of his own 'reading illness'. He is 'infected' by the masculine literary canon, which in his mind entails literary superiority over Catherine and his sister Eleanor.

Storytelling as therapy is a term that connects literature and trauma into a method of organizing experience. My analysis will focus on a selection of dialogue between the main characters and Henry's monologues, to highlight where Austen's hero is compelled to take narrative control as a way to control his own trauma; his troubled relationship with his father and the death of his mother.

It is a truth universally acknowledged, that reading literature makes us better persons. At least, that is the grounding principle of the medical humanities field (Evans & Finlay: 2001), and its sub-category literature and medicine (Bernhardsson: 2010), in encouraging interest in books about illness, grief, loss, coping and death. Embedded within these texts, lie codes of transference from which the reader gains empathy, knowledge, sympathy, recognition, not to mention understanding. While the premise seems utopian, arguably novels using illness as a theme, rather than a subject, can help readers understand how we interact and engage with each other, encourage healthy, sustainable habits, and how we can treat each other better.

To explore this thought, I will do a reading of Jane Austen's 1818 novel, *Northanger Abbey*, which focuses on the experienced reader and storyteller, Henry Tilney. I propose a reading of the novel where the Gothic and the medical work together to highlight gendered practices of incarceration, pathologising and narrative as therapy (Cavallaro: 2002). This article reads Henry Tilney as a type of mesmeric healer who wants to heal Catherine of her unhealthy obsession with Gothic novels. His method, however, unveils the dark side of the society he accolades. As he creates the narrative of his and Catherine's story, he uncovers the dark narrative he, in emulating his father, propagates to avoid dealing with his own trauma, namely the death of his mother.

Pathographies are personal, subjective narratives of illness; illness narratives as a more open term includes perspectives like the next-of-kin, a friend, a parent, a medical practitioner etc. I am not arguing, that *Northanger Abbey* is an illness narrative or a pathography, but the novel arguably problematizes gendered practices of dealing with various illnesses. My contribution is to examine *Northanger Abbey* in light of the historical discourse of infectious literature, to offer an alternative to more traditional readings of the novel as a mere satire of the Gothic genre. While there are other examples of trauma and illness in literature, opening up for other readings of Austen's *juvenilia* in the context of literature and medicine (Bernhardsson: 2010; Evans & Finlay: 2001) will ultimately benefit both Austen-research, Gothic research and medical humanities as a field.

Gothic Health and Illness

Northanger Abbey, along with *Persuasion*, were Jane Austen's last published novels, as part of a single volume published in November 1817[1]. The former, however, was originally ready for publication in 1803 (Irvine: 2005, 40-41). *Northanger Abbey* is the story of Catherine Morland and the Tilney family who live in a converted abbey. Catherine is obsessed with Gothic novels, and therefore suspects that Northanger is the site of murder and secrets. Despite her misreading, the novel concludes with Catherine and Henry Tilney marriage. The novel is predominantly known as a parody of Gothic pioneer Ann Radcliffe's novel *The Mysteries of Udolpho* (1794). Radcliffe had brought respectability to the heavily criticized genre by adding a moral ending to counterbalance the supernatural elements associated with Gothic narratives. Nevertheless, the Gothic novel was not considered 'proper' fiction, and the content of Austen's novel situated itself in direct opposition to the ruling notion of 'high' literature, a notion that tried to exclude the *novel* as a literary genre (Michael: 1982, 206).

Why were Gothic novels considered inappropriate literature beyond its lack of educational principles or adherence to the laws of nature and physics? I would echo Anne Williams and say that this fear of the Gothic is actually the fear of the all-powerful *"female. All Gothic trappings – ruins, graves, dark enclosures, madness, even the sublime – signify the presence of this 'other'"* (Williams: 1995, xi). The moon's mythical ability to turn men into werewolves, the darkness to birth monsters, is a power associated with the feminine in most Western traditions, and the moon's cycle reflects in women's menstrual cycles. In other words, the Gothic might be fraught with symbols of femininity and thereby become mouthpieces for the female experience under a patriarchal rule. Furthermore, the genre was considered dangerous, because of its increasing, almost infectious, popularity. The Gothic novel gained popularity in England alongside the scientific advancements of the Enlightenment. To quickly summarize the tropes and components of the Gothic narrative:

> *"[A] Gothic tale usually takes place (at least some of the time) in an antiquated or seemingly antiquated space – be it a castle, a foreign palace, an abbey, a vast prison, a subterranean crypt, a graveyard, a primeval frontier or island. . . . Within this space, or a combination of such spaces, are hidden some secrets from the past (sometimes the recent past) that haunt the characters, psychologically, physically, or otherwise."* (Hogle in O'Malley: 2011, 82)

Using *Northanger Abbey* as a case study carries with it certain risks; it stands, as mentioned, as *the* emblematic Gothic parody. Other research has focused on the novel's antagonist, General Tilney (Williams: 1998), the archetypal patriarch. Henry Tilney's role has been hailed either as Austen's feminine hero (Eddleman: 2010), or as the true villain of the novel (Gilbert & Gubar: 1979). It is beyond the scope of this article to give a full account of the novel's reception and criticism, but my contribution will be to re-examine the character of Henry Tilney in terms of readership, infectious literature and masculinity.

First, a quick abstraction of the etiological understanding of illness in 18th- early 19th century. The understanding of how illness spread in the late 18th -century to mid-19th century was influenced by the work of Franz Anton Mesmer (1734-1815) and his thesis on animal magnetism.

> "*(1) A subtle physical fluid fills the universe and forms a connecting medium between man, the earth, and the heavenly bodies, and also between man and man. (2) Disease originates from the unequal distribution of this fluid in the human body; recovery is achieved when the equilibrium is restored. (3) With the help of certain techniques, this fluid can be channelled, stored, and conveyed to other persons. (4) In this manner, 'crises' can be provoked in patients and diseases cured.*" (Ellenberger: 1970, 62)

While Mesmer's work is primarily associated with the placebo effect (Helman, 2004: 50-51), it is as much part of the historic makeup of *Northanger Abbey* as the reverberations of the French revolution was. The idea that a person could influence another to the point where one could cure disease is borderline supernatural, and fits snugly in the Gothic domain, even if the effects produced really stems from the charisma of the healer. Henry Tilney is continuously described as a charming character, most of all in Catherine's opinion. As time progresses, Henry realizes that Catherine's obsession with Gothic novels are detrimental to her status and prospects as a wife, as they encourage a more adventurous and unfeminine ideal. Like the charismatic healer he is, Henry must produce a 'crisis' to cure her and ensure her status as an angel in the house, rather than the madwoman in the attic (Gilbert & Gubar: 1979). However, his plan backfires. I contend that in trying to heal Catherine of her Gothic infection, Henry inadvertently enables himself to deal with his own troubled past, and more importantly, his present.

Dark Narratives

Much like the modern pathography (Frank: 2013; Hunsaker Hawkins: 1993), one goal of the Gothic is to provide a voice for those who have been silenced, by either societal, familial, physical or mental causes. Female-centric narratives share a unique position in this regard. Many of the tropes that characterize the Gothic novel are metaphorically comparable to life in incarceration, be it in a whalebone-corset or behind the iron bars of a prison or a mental institution. The haunted castles, mysterious apparitions, isolation, a threatening masculine presence might seem obvious allegories to the social constrictions that governed the gendered relations of Regency society. One factor that remains steadfast throughout was health or rather 'ill health'. It is interesting to note, that some of the most respected and well-read female authors of the 19th -, and 20th centuries produced such narratives as to shed light on the lack of understanding for female ailments, and the horror of the medicalization of women, body and mind (Charlotte Brontë *Jane Eyre* (1847), Charlotte Perkins Gilman *The Yellow Wallpaper* (1892), Sylvia Plath, *The Bell Jar* (1966).

Sandra Gilbert and Susan Gubar's seminal work *The Madwoman in the Attic* demonstrated how patriarchal socialization negatively affected women's mental and physical health. "*To be trained in renunciation is…to be trained to ill health*" (1979: 54), that is to say, to be born female was to be institutionalized from day one, simply moving from one patriarch to another. Young girls were trained to be sickly, frail, self-deprecating, self-less (literally without self), still, and pretty. A 'healthy' woman was unnatural and did not comply with the contemporary mythology that portrayed women as angelic beings, too pure for earthly life. Poor health was a sign of delicate breeding, "*to be ladylike is to be lifeless*" (Woolsen quoted in Dijkstra, 1986: 27). Becoming ill was not merely a by-product of the patriarchy; it was the goal (Gilbert & Gubar: 1979, 54). I argue that medical humanities and the Gothic share a literary purpose in this respect, since "*Gothic representations are not realistic: they represent highly subjective [sic], the fraught experience of crisis*" (Wasson & de Borba: 2018).

Freud's concept of the *unheimlich* is a key concept in the Gothic. The *unheimlich*, if literally understood as 'not home', or 'unhomelike', begets a, sometimes uncomfortable, understanding of the home as a permutable place; it can transform and defamiliarize a space that should exude safety and warmth. 'Home' can be a house but it is ultimately the people that truly make a 'home'. That leads me to the notion of family in the Gothic, as well as the (lack of) rights of women in Gothic homes, and in England at large.

> *"In the unremittingly economic Female Gothic, the Gothic is shown to reside in the everyday in the form of women's commodification… Notably, the traditional Gothic dynamic is subverted in this more modern of Gothic fictions [Northanger Abbey], as the sins of the materialistic father are not visited upon his son."*
> (Davison: 2010, 163-164)

'The sins of the father are revisited upon his son' is the credo of the Gothic. Catherine's infamous misreading of the Gothic genre highlights the fragile domestic position of women like Henry's mother. Her sudden death erased her from every public area of the house and her children rarely speak of her, except in hushed tones away from their borderline tyrannical father. It is with these conditions in mind that Henry was brought up; after the death of his mother, he could escape into a profession, the clergy and his brother to the military (and other extra-curricular activities). His sister Eleanor, however, had to remain at the abbey, almost as if she were to return to its monastic roots. Unable to marry the man she loves, she remains under her father's strict regime. The focus of this article is not Eleanor's story, but Henry's, because I want to give an alternative reading to Gilbert and Gubar's rather narrow understanding of his character, which my dual approach, medical humanities and the Gothic, enables me to do.

Austen has imbued Henry's ancestral home, Northanger Abbey, with certain qualities reminiscent of a hospital/asylum or a prison, e.g. meals are served at specific times, Catherine's and Eleanor's days are regulated, as well as their activities and freedom of movement. The novel essentially makes the young women (and man) living in the Abbey either a patient or a prisoner, governed by General Tilney. The abbey is, therefore, a source of patriarchal contamination which entails that the general is 'patient zero'. He is the main representative of the pathologizing patriarchy that seeks to 'infect' Catherine. However, Catherine's infatuation with Gothic novels proves to be her and Henry's salvation

Catherine's introduction to the Abbey is through Henry. Having established that he is the more experienced reader, he thinks he is able to control the narrative and thus agitates her imagination with a tall tale of what will befall her when they enter his ancestral home:

> *"[Are] you prepared to encounter all the horrors what a building such as 'what one reads about' may produce? […] Will not your mind misgive you, when you find yourself in this gloomy chamber […] How fearfully will you examine the furniture in your apartment!"* (Austen: 1818, 161-162).

He goes on, describing an old malignant housekeeper, a locked cabinet, a broken tapestry and a torn manuscript relating the fate of "*wretched Matilda*" (Austen: 1818, 164), all trademark staples of a Gothic narrative[2]. Henry is stoking Catherine's imagination to induce the necessary crisis to expel her unhealthy obsession with Gothic novels. However, Catherine suspects the General of having either killed or imprisoned his wife. Her suspicions result, not in a violent altercation but a rational (albeit heated) dissemination of facts by Henry (Austen: 1881, 202-203), a scene we shall return to in detail shortly.

Storytelling as Therapy

As mentioned, the General runs his household with military precision. He is zealously renovating and modernizing the abbey, which separates him further from his son. The General's profession is to order people; Henry's is to guide them. He is like his father in many ways but more like his sister in others. Where his father taught him to control, his sister taught him to nurture and this is just as important a lesson, as we will see in the next section, the "*mental asylum closely approximates the female rather than the male experience within the family.*" (Chesler: 2005, 95)

Most scholars agree, that Henry serves as an educator, a mentor for Catherine[3]. Within medical humanities, Martyn Evans emphasises the importance of education rather than training (2003: 383), which is interesting, as Catherine considers herself as a 'heroine in training'(Austen: 1881, 7). I read Henry as a 'the healer' who sets out to cure Catherine of her unhealthy obsession with Gothic narratives. The meeting between patient and doctor is always an interpretive activity, a hermeneutical challenge (Bernhardsson: 2010, 50), which I think is as true of how Catherine and Henry interact. Through conversation, their opinions, personalities and experiences (or lack thereof) highlight their characters and their epistemological differences. This leads to a perpetual renegotiation of each character's equilibrium; in other words, in search of equality, or at least as much as an 18th-century couple could be equal.

Henry Tilney is an apt conversationalist, he talks with *"fluency and spirit"* (Austen: 1818, 17) on the night he is introduced to Catherine Morland in Bath. Having chatted amiably and freely for a while, he suddenly changes the subject and instructs Catherine in the 'correct' manner of discussion, i.e. he is re-writing their previous conversation into a less genuine, but socially preferred manner of conversing:

> *"I have not yet asked you how long you have been in Bath; whether you were ever here before; whether you have been at the Upper Rooms, the theatre, and the concert, and how you like the place altogether. I have been very negligent—but are you now at leisure to satisfy me in these particulars? If you are I will begin directly."* (Austen: 1881, 17-18)

More often than not, his arguments about style and proper aesthetic thought are derived from the masculine canon of conduct, through the discourse of 18th-century essayists such as Joseph Addison, Samuel Johnson and Samuel Richardson. He can balance his interaction with a predominantly female literary canon with *"the* discourse *of the Johnsonian essay"* (sic Irvine: 2005, 44). As an experienced reader, and as an experienced man in society, Henry puts Catherine at a strong disadvantage. Robert P. Irvine argues, that the male essayists mentioned above have as much power over Henry's world-view as Radcliffe has over Catherine's (2005, 44) but I would argue; that being a well-read man does not have the same connotations as being a well-read woman. The narrator frequently mentions, that Catherine is well-read, *"provided that nothing like useful knowledge could be gained from [books,] that they were all story and no reflection"* (Austen: 1881, 7). I will however build upon Irvine's next point, that Henry uses Johnsonian *discourse*, as a

> *"linguistic version of the patriarchal power of the General: a way of controlling women, not physically by locking them up or removing them from a house, but by controlling their language, telling them what they may and may not say"* (Irvine: 2005, 44-45).

Irvine points to Henry's speech patterns as "natural" (Irvine: 2005, 46), as in, he is using speech and narration to confirm both his and Catherine's status as belonging to a privileged social group and this language is a result of the masculine canon of polite society. In other words, Henry uses language and by extension to alter the narrative that his sister, and Catherine, originally use about their own condition. He displays his mastery of the language, and of the Gothic genre, to exert control, and to dominate the conversation, like in this scene:

> *"…I myself have read hundreds and hundreds. Do not imagine that you can cope with me in a knowledge of Julias and Louisas. If we proceed to particulars, and engage in the never-ceasing inquiry of 'Have you read this?' and 'Have you read that?' I shall soon leave you [far] behind me…Consider how many years I have had the start of you."* (Austen: 1818, 108)

Catherine then turns to Eleanor and tells her of something horrid that is about to emerge in London. She refers to the publishing of a new novel "*in three duodecimo volumes, two hundred and seventy-six pages in each, with a frontispiece to the first, of two tombstones and a lantern*" (Austen: 1818, 114), but Eleanor thinks she is talking about a riot. Henry intervenes: "*shall I make you understand each other, or leave you to puzzle out an explanation as you can? No—I will be noble. <u>I will prove myself a man</u>...*" (my italics, ibid). He is raising himself as a benevolent arbiter and the most well-read of the three he must, therefore, be the most capable person to reinstate reason and logic where before there was chaos and confusion. What the Gothic symbolizes, is chaos, loss of control and subjugation of free will, as history is bound to repeat itself (sins of the father, etc).

> *"All illness and unhappiness generate their own very special types of tale. This is because telling a story is one of the most basic human ways of organizing experience – and of shaping suffering into a form, in order to give it meaning"*[4] (Cecil Helman qtd in Cavallaro: 2002, 125).

I argue, that this is what Henry is doing; he shapes his ideas and world views on the male, 'rational' canon of literature that occludes female experience and fanciful tales.

When Catherine tries to bring the conversation back to a level she can engage on, Henry picks on her use of the word 'nice' and reroutes the conversation once again. Eleanor reproaches her brother:

> *"…he is treating you exactly as he does his sister. He is forever finding fault with me, for some incorrectness of language, and now he is taking the same liberty with you. The word 'nicest', as you used it, did not suit him; and you had better change it as soon as you can, or we shall be overpowered with Johnson and Blair"* (Austen: 1818, 109).

Note that Eleanor says "overpowered" by these male writers. The right sort of knowledge will then enable you to overpower and overthrow and one might argue that Eleanor is chastising her brother for employing the same domination techniques as their father:

> *"-Well, Eleanor, may I congratulate you on being successful in your application to your fair friend?*
> *- I was just beginning to make the request, sir, as you came in.*
> *- Well, proceed by all means. I know how much your heart is in it. My daughter, Miss Morland," he continued without leaving his daughter time to speak…"*
> (Austen: 1818, 110)

This passage echoes William's opening statement (1995, xi), the fears of the 18th century concerning the effects of female novel-reading, results in a fear of female autonomy and authorship, not just in terms of literature, but in personal narration. Her father will not let her speak and now Henry is attempting to do the same. Interestingly, Henry does not speak further in the conclusion of the chapter as Eleanor (and the narrator) cuts him off, "*We shall get nothing more serious from him now*" (Austen: 1818, 115).

This need to control the conversation, at least, to stand at its helm, indicates a deeper need for control, which can stem from a trauma of some unresolved helplessness in the past. It is a natural response to the death of a loved one as one cannot prevent the inevitable, nor retake what Death has claimed. I propose that Henry's way of dealing with the conditions of his patriarchal society is to take the narrative control throughout the novel. However, as he mocks his sister for fearing for their brother's safety he goes into excruciating detail. I consider this attention to detail to be representative of Henry's infatuation with the Gothic, and his ability to spin a tale to his advantage, namely to subconsciously deal with his present, but also his past. Cavallaro in her book *The Gothic Vision* (2002) reworks Freud's understanding of storytelling as a therapeutic measure (Cavallaro: 2002, 123-125) and outlines some ways in which storytelling and narrating creates space and opportunity to articulate both *"personal and communal apprehensions of darkness"* (Cavallaro: 2002, 125). Henry's family may not be as dark and convoluted as most Gothic archetypes, but one can be certain of one thing; most children will copy their parents' behaviour. Perhaps Henry's heroic flaw is not realizing how close he has come to do just that.

Producing a Crisis

Henry reveals, that the cause for his mother's death was an illness from which his mother had suffered previously. Asked if his father was truly affected by this traumatic event, he falters, *"He loved her, I am persuaded, as well as it was possible for him to – We have not all, you know, the same tenderness of disposition –"* (Austen: 1818, 202-203). He clearly is at a loss for words; not only must he defend the character of a man on whose good graces he depends but also a man with whom he already has a strained relationship. After Mrs Tilney died, her presence, her portrait, the very mention of her name is occluded from their surroundings. One might infer, that her death was mourned privately and subdued, the repercussions of which are yet unprocessed.

When Henry learns of Catherine's suspicions about his father, he succinctly deconstructs her inference that his father is a Montoni-like character[5], on all counts. Kidnappings, incarceration and torture surely cannot occur in England, the powerhouse of the British Empire, this bastion of culture, education, printing culture and neighbourly gossip. Henry displays his ignorance in this area as Catherine does; these things *did* happen and some of them were sanctioned by law. Husbands could technically 'kidnap' and commit their wives to mental asylums, few to no questions asked, in the 17*th*-18th century. The strongest literary examples of this are *Jane Eyre* (Brontë: 1847) and *A Whisper in the Dark* (Alcott: 1889), where we find women unfairly committed to incarceration, one familial, the other institutional.

However, as much as Henry would like to criticize Catherine's understanding of patriarchal abuse of women, he is erroneous in his assertion that England is above such practices.

> *"Remember that we are English, that we are Christians…Could they be perpetrated without being known, in a country like this, where social and literary intercourse is on such a footing, where every man is surrounded by a neighbour-*

> *hood of voluntary spies, and where roads and newspapers lay everything open? Dearest Miss Morland, what ideas have you been admitting?"* (Austen: 1818, 203)

Here, I would argue, that Henry's argument relies too much upon the understanding that the upper classes all acted benevolently towards those less fortunate. Daniel Defoe back in 1687 had seen the disgusting abuse of people who were put in asylums, oftentimes for simply exerting contemporary inappropriate behaviour, and called it *"the height of Barbarity and Injustice in a Christian Country"* (my italics, Fadul: 2014, 67; Szasz: 2007).

Essentially, what Henry is saying, is that the tenets of the Enlightenment and print culture have rendered the horrors of the Gothic harmless. The power of Radcliffe's Gothic aristocrats to kidnap, murder, exploit and terrorize have diminished, if not evaporated in the light of a new age of progress. The General is a tyrannical patriarch in many respects and Henry, tellingly, skirts this issue. Instead, his focus remains on Catherine and *what she has let herself believe* about herself and the world. I argue, that Henry's agitation is not just concerning Catherine's accusations of his father's cruelty but at the *ideas* that the language of sentimentality and horror, the language of female subjugation and patriarchal abuse, allows Catherine to give voice to the madwoman in the attic. As we have seen, no one would question any and all punishment or subjugation of the women in his family. Perhaps he also baulks at the insinuation that the sins of the father will be repeated in Henry. The moment is therefore crucial in Catherine's *and* Henry's character-development.

After the crisis has been induced in Catherine, all thoughts of romance are over, and arguably Henry's character is more attuned to hers. She is in need of comfort, which Henry happily provides, and all their conditions improve when the general leaves the abbey:

> *"The happiness with which their time now passed, every employment voluntary, every laugh indulged, every meal a scene of ease and good humour, walking where they liked and when they liked, their hours, pleasures and fatigues at their own command, made her thoroughly sensible of the restraint which the general's presence had imposed, and most thankfully feel their present release from it."* (Austen: 1818, 227)

The General's regime was clearly not the cure for Catherine's 'illness' and, I argue, that this becomes clear to Henry as well as both Catherine and Eleanor are empowered by the General's absence. Notably, Henry's manner of talking changes, or rather, the way he is narrated changes. After the General expels Catherine from the abbey for the crime of being less rich than he had thought her to be, Henry travels to Catherine's home to ask for her hand. He has broken with his father, and now talks "*without sense of connection*" (Austen: 1818, 253) and any other dialogue on his part is recounted by the narrator, not by Henry himself. He is no longer trying to control the story, neither his nor Catherine's. In trying to 'cure' Catherine using patriarchal techniques their dialogue affected real change within him.

Concluding remarks

This article has read Henry Tilney as a mesmeric healer who is out to cure his patient, Catherine, using literary tropes. His method is an amalgam of the style of his father, who has turned his 'home' into a semblance of an institution or a prison and the style of the male literary canon by Johnson and Blair. Catherine is certain that Mrs Tilney is kept prisoner by the General, and while her theory is far from watertight, I would argue that she is only mistaken in terms of *who* is kept prisoner; Eleanor Tilney. Henry, by virtue of his gender, has a longer leash. If we agree, that the preferred mode of femininity was to be ill/sick, fainting, shopping or playing delicate music to please in familial circumstances, then Catherine's active outdoorsy youth is a strike against her. She is *healthy*; in itself an indicator of abnormal femininity in her time. Henry picks up on this and exudes a certain magnetism that Catherine finds irresistible (Austen: 1818, 134). In order to make Catherine into a suitable bride/woman she must conform to patriarchal, or perhaps more accurately, cultural (i.e. masculine) understandings of the female being. Henry's goal, in the tradition of mesmerism, must create a crisis in Catherine's body that will expel the disease, only then could they be united. Catherine likes Gothic novels; so therefore, he will spin a Gothic tale, to drive her, sweating and spasmodic into "healthy" reading habits. However, as his control of the narrative was upset by Catherine's 'illness', he inadvertently produced a crisis in himself, thereby becoming a 'patient'. This is a fortuitous outcome, as it will enable him to distance himself from people who represent values like subjugation, blind obedience and misogynistic practices and truly embody Austen's hero.

The Gothic novel, as *Northanger Abbey* neatly demonstrates, is not meant to be read as an exposé of the darker side of the human psyche. It is a satire, an hyperbole and a perversion of relationships, gender roles and sexuality. I would argue, that Henry as an experienced reader knows this but perhaps forgot that the point of satire was in part to criticize contemporary society. The Gothic definitely critiques many facets of 18th and 19th-century practices which engendered an eschewed understanding of 'natural' and 'unnatural'. I posit that Austen's hero decided that he would not follow in his father's footsteps but set out on a path of his own, guiding and letting himself be guided.

Notes

1 The dating of this novel is not straightforward, see Irvine (2005, 40). As mentioned, it was published posthumously in December 1817, but the cover page states 1818 as its publishing date.

2 The mention of the manuscript is a quintessential Gothic trope, as it harkens back to the first Gothic novel, *The Castle of Otranto* (Walpole, 1764), which was published as an 'uncovered manuscript'.

3 This essay explains this very well: http://ou.edu/expo/brainstorm/_jcr_content/contentpar/download_38/file.res/Garbarino-Power%20Patriarchy%20Henry%20Tilney.pdf

4 Cavallaro quotes Cecil Helman (1992), *The Body of Frankenstein*, New York: Norton.

5 The villain from Radcliffe's *Mysteries of Udolpho*.

References

Alcott, L.M. (1889). *A Modern Mephistopheles and A Whisper in the Dark*. Boston: Roberts Brothers.

Austen, J. (1818). *Northanger Abbey*. (2006) Cambridge: Cambridge University Press. https://doi.org/10.1093/oseo/instance.00080854

Bernhardsson, K. (2010). *Litterära besvär - Skildringar av sjukdom i samtida svensk prosa.* Polen: Ellerströms förlag.

Brontë, C. (1847). *Jane Eyre*. (2006) England: Penguin Classics. https://doi.org/10.5117/9781904633037

Cavallaro, D. (2002). *The Gothic Vision: Three Centuries of Horror, Terror and Fear.* New York: Continuum.

Chesler, P. (2005). *Women and madness*. (2018) Chicago: Lawrence Hill Books.

Davison, C.M. (2010). *History of Gothic Literature: Gothic Literature 1764-1824*. (2nd): University of Wales Press.

Dijkstra, B. (1986). I*dols of Perversity: Fantasies of Feminine Evil in Fin-de-Siècle Culture*. New York: Oxford University Press.

Eddleman, S.M. (2010). *Henry Tilney: Austen's Feminized Hero? Persuasions*. www.jasna.org: Jane Austen Society of North America.

Ellenberger, H.F. (1970). *The Discovery of the Unconscious. The History and Evolution of Dynamic Psychiatry*. London: Basic Books.

Evans, M. (2003). Roles for literature in medical education. *Advances in Psychiatric Treatment*, 9, 380-385. 10.1192/apt.9.5.380. https://doi.org/10.1192/apt.9.5.380

Evans, M., & Finlay, I.G. (2001). *Medical humanities*. London: BMJ Books.

Fadul, J.A. (2014). *Encyclopedia of Theory & Practice in Psychotherapy & Counselling.* New York: Lulu Press Inc.

Frank, A.W. (2013). *The Wounded Storyteller: Body, Illness, and Ethics*. (2nd ed.) Chicago: University of Chicago Press.

Gilbert, S.M., & Gubar, S. (1979). T*he Madwoman in the Attic: The Woman Writer and the Nineteenth-Century Literary Imagination.* (2000) New Haven: Yale Nota Bene.

Helman, C. (2004). *The Body of Frankenstein: Essays in Myth and Medicine*. New York: Paraview.

Hunsaker Hawkins, A. (1993). *Reconstructing Illness: Studies in Pathography*. Indiana: Purdue University Press.

Irvine, R.P., (2005). *Jane Austen*. London: Routledge. http://ebookcentral.proquest.com/lib/tromsoub-ebooks/detail.action?docID=200364

Michael, M. (1982). The Novel and Its Critics in the Early Nineteenth Century. *Studies in Philology*, 79, 205-226.

O'Malley, P. (2011). »Gothic«. In Gilbert (Ed.), *A Companion to Sensation Fiction*. West Sussex, England: Wiley-Blackwell. https://doi.org/10.1002/9781444342239.ch6

Radcliffe, A. (1794). *The Mysteries of Udolpho.* (2008) New York: Oxford University Press.

Szasz, T. (2007). *Medicalization of Everyday Life: Selected Essays*. New York: Syracuse University Press.

Walpole, H. (1764). *The Castle of Otranto: a Gothic Story*. (1998) Oxford: Oxford University Press.

Wasson, S., & de Borba, A., (2018). *»Medical Humanities Intersections with Gothic Studies«*. https://www.atmostfear-entertainment.com/health/practices/medical-humanities-intersections-gothic-studies/#, 20.09.2018. (Web)

Williams, A. (1995). *Art of Darkness: A Poetics of Gothic*. Chicago: University of Chicago Press. https://doi.org/10.7208/chicago/9780226899039.001.0001

Williams, C.D. (1998). General Tilney and the Maidens All Forlorn: Typecasting in Northanger Abbey. *Women's Writing*, 5, 41-62. https://doi.org/10.1080/09699089800200027

Medicalized Literary Criticism in Fin de Siècle Norway

Johan Scharffenberg and Henrik Dedichen as 'Medics-as-Critics'

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Medicalized literary criticism was a widespread phenomenon across Europe in the decades surrounding the year 1900. The term describes varied practices of literary criticism founded on medical terminology and imagery. Critics with different professional backgrounds participated in this type of criticism, often by connecting medical analogies to established notions of fin de siècle decline and decadence. This article explores the proliferation and various uses of medicalized literary criticism in Norway in this period, including a case study of the literary criticism and discussion performed by two Norwegian psychiatrists and asylum doctors, Johan Scharffenberg and Henrik A. Th. Dedichen. I argue that these 'medics-as-critics' responded and contributed to the medicalized literary criticism and, by extension, to the establishment and prevalence of certain illness narratives in the public sphere.

In the 1890s Norwegian public sphere, the field of literature and literary criticism functioned as a meeting place where contributors with different professional backgrounds discussed the borderland between culture, science, and society through medical analogies. This practice, which I will refer to as *medicalized literary criti-*

cism, is part of a general 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. The term describes varied practices of literary criticism founded on medical terminology or imagery, published in books, journals, or the daily press. In Norwegian literary studies, this remains uncharted territory despite the fact that literary criticism was consolidated in Norway at this time.

All kinds of medicalization understood as a sociological and cultural phenomenon surpass the boundaries of the medical field itself, its epistemology and its areas of responsibility (Bondevik, Madsen & Solbrække, 2017: 15-16). Medicalized cultural practices should therefore not be understood merely as popularized varieties of medical discourse; they operate independently, facilitating and producing meaning in their own right and can, in turn, influence the medical field. In the context of Norwegian medicalized literary criticism, contributors had their background in fields such as literature, history, medicine, and law. Through medical analogies, they often connected their literary assessments to established notions of *fin de siècle* decline and decadence.

I will begin by exploring the wider contextual background of the critical practices that can be ascribed to the concept of medicalization, before moving on to a case study of the literary criticism performed by two Norwegian psychiatrists and asylum doctors, Johan Scharffenberg (1869–1965) and Henrik Arnold Thaulow Dedichen (1863–1935). Their literary assessments take place in the borderland between medicalized cultural practices and the emerging field of psychiatry. By analyzing how these two 'medics-as-critics' responded and contributed to the medicalized literary criticism and, by extension, to the establishment and prevalence of certain illness narratives in the public sphere, I wish to contribute to the current revisionist approach to medicalization within cultural and literary studies. Medicalized practices deserve to be studied in their own right as productive participants in the cultural sphere and not solely—in the tradition of Foucauldian discourse analysis—as symptoms of professional imperialism or social control (cf. Madsen, 2017). In the public domain, the interactions of literature and medicine were complex and productive, facilitating new ways to understand and approach the anxieties and needs of the *fin de siècle*.

Medicalized criticism and the 'disease of the century'

Medicalized literary criticism stems from an increasingly medicalized culture, internationally and in Norway. In *Samtiden*, a journal known to have consolidated Norwegian literary criticism at the time (Thon, 2016), illness was a regular topic. For one of the journal's frequent contributors, Guglielmo Ferrero, the end of the century called forth one question above all: *Are we sick?* In a translated article with this very title, "Er vi syge?" (1893), Ferrero points toward a culture in which disease and deviancy form the topic of every text produced in literature and philosophy as well as science. "*One becomes quite dizzy and confused to see so many unfortunates and sick in all kinds of books*," he writes (1893: 362, my translation).[1] Identifying degeneration as the 'disease of the century', Ferrero blames degeneration theory for the universal interest in illness and abnormality among "*[s]cholars, poets, artists, all who think and produce*" (ibid.). His most prominent examples are taken from the world of fiction, where authors from Émile Zola and Fyodor Dostoevsky to Henrik Ibsen write of degenerative madness and illness inspired by men of philosophy and science such as Hippolyte Taine and Cesare Lombroso. Yet, Ferrero himself is unconvinced that "*all the world's a hospital*" (ibid. 361). The population at large is not sick, Ferrero concludes; it is instead the stories and studies of illness that have increased.

In this way, Ferrero draws attention to the complex and multifarious ways in which culture responds to and shapes how we perceive disease, and how these perceptions might change society itself. The twentieth century would come to see several periods in which stories and studies of certain conditions and illnesses increased and were understood through specific analogies. Susan Sontag put forward similar observations in her famous 1978 work, *Illness as metaphor*, in which she critically explored the metaphors and mythologies created around diseases such as AIDS and cancer. Likewise, medicalization and illness narratives seem to be on the rise in our own time (Jurecic, 2012; Bondevik, Madsen & Solbrække, 2017). Ferrero's articles show that similar questions and debates flourished at the *fin de siècle*, where degeneration served as a collective term for a wide array of conditions, deviancies, and diseases. In a Norwegian or Nordic context, studies of such varied phenomenons as decadence (Andersen, 1992; Buvik, 2001), melancholy (Johannisson, 2009), hysteria (Bondevik, 2005, 2007, 2009; Bondevik & Stene Johansen, 2011), tuberculosis (Jørgensen, 2014), and criminality (Warberg, 2016) all relate them to this 'disease of the century' but a cultural history of the concept has yet to be written.

Degeneration theory played an important role in blurring the lines between popular and scholarly attitudes toward illness in the latter part of the nineteenth century, thus facilitating a general medicalization in the public sphere. Degeneration theory, originally a biological and medical theory launched by Bénédict-Augustin Morel in 1857, held that, a wide variety of deviancies were caused by alcoholism or immoral behaviour and that these deviancies could be inherited and result in increasingly serious forms of abnormality until the family line went extinct (1857: 5). The concept of degeneration coexisted, co-developed, and often overlapped with theories of evolution, including Lamarckism, Spencerism, and Darwinism. By the 1890s, it had become a contested but widely recognized term within sciences, philosophy, and the arts across Europe (Pick, 1989). Degeneration had also become a rhetorical device in politics and a term of everyday discourse (Chamberlin & Gilman, 1985: xiii; Pick, 1989: 6). Degeneration theory was well known in the Norwegian public by the time Ferrero published his article (Warberg, 2016), although, it was increasingly criticized by scholars across Europe.

Within the framework of biological degeneration, types such as the diseased, the insane, the criminal, the sexually deviant, the decadent, or the ingenious met in a single cultural figure 'the degenerate.' This figure served as a universal patient infected with what Ferrero called the 'disease of the century' which could be interchangeably physical, psychological, and moral in nature (1893: 361). Seen through the lens of degeneration theory, illness narratives were ubiquitous in public discourse and contributed to the production of meaning far beyond the scope of individual patients or somatic disease. The widespread medicalized discussion and criticism of literature, in which meta-assessments such as Ferrero's appeared frequently, added to this impression. The debate on illness and literature was both interdisciplinary and internationally oriented. Ferrero's article in *Samtiden* is a case in point: it had first been published in French in *Revue des Revues*, then paraphrased and commented on in Norwegian newspapers, and eventually translated for the Norwegian journal.[2] Ferrero, a historian and criminal anthropologist by profession, published widely on both cultural and scientific topics throughout Europe.

At the heart of medicalized literary criticism was the question of, how one should understand the many illness narratives appearing across the scientific and cultural spheres of society. Did these suggest, as Ferrero asked, that everyone had become ill, or was it just philosophers and authors, or just their works? In other words, if degeneration was the disease of the century, who were the patients? Medical literary criticism offered several answers to this question: the patient could be the author, who gave his characters the traits he knew from his own life experience; the readers, influenced and infected by the literary representations of disease and abnormality; or the text itself, to be diagnosed as unhealthy and marked as contagious. Who and what were degenerated, and to what effect or with what potential cure, were recurring questions, resulting in varied attempts to read and assess literature in medicalized ways.

Internationally, the most (in)famous example of medicalized criticism concerned with degeneration is the German physicist, author and journalist Max Nordau's *Entartung* (*Degeneration*) from 1892–1893. This highly popular work analyzed literature in light of degeneration theory, on the premise that "[*d*]*egenerates are not always criminals, prostitutes, anarchists, and pronounced lunatics; they are often authors and artists*" (1993 [1892]: v). Treating the text as body and the author as a patient, Nordau diagnosed several contemporary authors, including Henrik Ibsen, with degenerative conditions. He advocated what he called a 'scientific criticism' meant to result in actual censorship of 'degenerated' authors and their works (1993: 557). Nordau's message of cultural hygiene immediately opened up his work to ridicule, but his theories were deemed significant enough to merit both reading and refutation (Pick, 1989: 25). Critics seldom denied the validity of degeneration theory itself but objected to Nordau's use of it.

In Norway, the cultural historian Christen Collin instigated a similar debate in 1894, often called the 'decadence debate.' In a series of articles later published in *Kunsten og Moralen. Bidrag til Kritik af Realismens Digtere og Kritikere* (Art and Moral. Contribution to the Criticism of Realist Authors and Critics) (1894), Collin objected to what he saw as a romanticizing of decadence, illness, and amorality in contemporary Norwegian literature. He wanted to combat this literary decadence through a scientific criticism meant to enlighten and warn readers, not unlike Nordau's claims. Collin made extensive use of medical metaphors: authors were ill, their books carried the disease, and readers, as well as society, could be infected (Collin 1894: 200). Unlike Nordau, Collin tones down the diagnosis of the author and ends on an optimistic note of Spencerism and vitalism (Buvik, 2003; Vassenden, 2012, 2016). Even so, the decadence debate retains clear connections to the medicalized literary criticism of Nordau and others (Hagen, 2013; Warberg, 2016). They all contributed to a new form of medicalized literary criticism differing from the established naturalism of Émile Zola and Hippolyte Taine: the role of doctor or scientist now befell the critic and not the author.

In the Norwegian daily press, the texts of Ferrero, Nordau, and Collin were discussed in light of one another.[3] Like other instances of medicalized literary criticism, they were widely read when published, to later become part of 'the great unread' (Cohen, 1999), the large mass of texts that were not canonized and were thus forgotten by literary historians. While Nordau's and Collin's works have been rediscovered in recent years, the tradition they were part of still requires examination. Another reason why medicalized criticism has seldom been studied in its own right may lie in the discourse itself. The above examples are similar in that they make use of biological theories and medical imageries in a blend of (pseudo)scientific language and metaphor that is difficult to detangle. Nordau is the extreme example of this but other contributions make use of similar rhetoric: authors are varyingly assigned the roles of patient, doctor, or scientist, while their texts are treated interchangeably as bodies, symptoms, experiments, sources of infection, and potential cures. While they come to different conclusions, these critics all tend to identify the effect of literature on society with that of disease and degeneration on its patient. Authors, readers, literature, and society variably become the patient in what constitutes a grand narrative of decline on both an individual and a societal scale.

While these medicalized critical practices and discourses are muddled at best, they are also highly productive in the sense that they explore the borderlines between knowledge, text, society, and individual. They also provide a corrective to the ideal of aesthetic autonomy within the literary field by insisting on literature's agency and responsibility as an important factor in shaping society—in other words, on the varied *uses* of literature (cf. Felski, 2008). Not least, they play important roles in establishing the boundaries of the many new professions of the era, such as psychiatry, sociology, and criminology, assigning them roles within the cultural sphere. This becomes particularly clear if we look to the contributions of actual medical professionals acting as 'medics-as-critics' in this period. Johan Scharffenberg and Henrik Dedichen are two examples of asylum doctors with cultural interests who sometimes operated as literary critics in the public domain. Their interest in the literature concerns individual authors as well as literature's role in society, not unlike Ferrero, Nordau, and Collin. As asylum doctors with medical educations, Scharffenberg and Dedichen are also interesting examples of professionals operating at the intersection of several emerging sciences.

Literary tinkerings – Johan Scharffenberg and Henrik Dedichen as 'medics-as-critics'

Johan Scharffenberg served as a physician and psychiatrist at various psychiatric institutions and prisons in Norway throughout his career. He was also a historian, politician, speaker, and writer, having published a collection of poems under the *nom de plume* Kai Lykke in 1889. In 1893, he began writing for the leftist newspaper *Dagbladet* under the pseudonym J. B. de Montaigu, primarily agitating against Norway's union with Sweden. His column was entitled "Politiske Kandestøberier" (Political Tinkerings), referencing Ludvig Holberg's satirical play from 1722. Several of Scharffenberg's articles from the 1890s also commented on the illness narratives of literary works and the practice of reading them in light of biomedical theories.

In 1894, Scharffenberg temporarily changed the title of his column to "Literære Kandestøberier" (Literary Tinkerings) and wrote an extended three-part literary criticism of Jonas Lie's novel *Niobe* (1893). The scope of the criticism was unusual, as the daily press seldom published literary criticism across several issues (Furuseth, 2016: 76). The fact that Scharffenberg changed his political column to make room for his review adds to the significance of this instance of medicalized criticism. His choice of novel, Niobe, served to heighten the actuality of his literary and disciplinary reflections. This long-awaited novel by a highly popular author was published right before Christmas in 1893. In February 1894 it was, in Scharffenberg's own words, "*talked about almost wherever you go*" (*Dagbladet* 1894.02.11). *Niobe* was widely perceived as a critique of modernity and generational decline. In it, a mother kills herself and three of her six children in response to her children's failure to become responsible adults in a new and modernized society and her own failure to prevent the family's decline (Midbøe, 1966). Unlike many realist and naturalist works of the period, the novel did not seem to blame the parents but modernity itself for the youths' decline.

Scharffenberg's review is 'scientific' insofar as it strives to treat the novel with objective distance and empirical methods. He made an impressive work of mapping what we would call the narrative's story level by ordering events chronologically and placing them in specific years. He also makes an inventory of the fictional family's probable income and economic status. Based on this analysis, he evaluates the novel's realism and identifies inconsistencies and implausibilities in the plot. This protostructural analysis is noteworthy, but it is the article's discussion of realist and naturalist narratives of decline that is most interesting within our context.

Scharffenberg praises Lie for not giving heritage a central role in *Niobe*. This is a sensible choice, he writes, given that *"inheritance of acquired traits is a largely contested dogma"* (1894b). That Lie avoids speculations on the heritable causes of the family's decline, is, to Scharffenberg, a sign of Lie's *"happy freedom from scholarly theoreticism"* (ibid.). The many literary genealogies and pathographies in contemporary literature are *"scientifically pure nonsense"* (ibid.), Scharffenberg claims, whether they stem from authors or from literary historians and critics:

> *"It is* ***Zola's*** *great mistake that he* quasi-*scientifically wants to explain his persons by their inheritance, which he NB. has bestowed on them himself. The value of the attempts by literary historians are not much greater (…) when they explain an author's personality from heredity and environment by Taine's method. "* (Scharffenberg, 1894b, my translation)

While Scarffenberg disagrees with the literary uses of biomedicine, he does not doubt the reality of hereditary and environmental influences. Like Ferrero, Nordau, and Collin, Scharffenberg saw human life, cultural life, and society as organic life-forms following the laws of nature (Scharffenberg, 1894b; Søbye, 2010: 126; 130-31). Unlike the examples we have seen so far, however, Scharffenberg's reading of *Niobe* does not perform a 'diagnostic' interpretation of the text. Instead, he explores the differences between fiction and reality, story and narrative through a detailed and methodological reading.

That said, Scharffenberg's later comments on art and literature come much closer to a diagnostic criticism of the kind practised by Collin and others. In a lecture in *Studentersamfundet* (The Student's Society) in 1895, he took the opportunity to diagnose Edvard Munch's art as *"diseased"* and the Norwegian youth as decadent (Søbye, 2010: 137). The lecture led to a short debate on the influence of decadence in the newspaper *Den 17 mai*, started by its editor, Rasmus Steinsvik. This debate repeats the most prominent stances of the decadence debate instigated by Collin the year before, echoing the discussion between him and author Arne Garborg, another editorial member of *Den 17. mai*. Scharffenberg repeats the main conclusions of his lecture on Munch and argues, like Collin, that literature may influence its readers and society. Steinsvik, on the other hand, concludes along the lines of Ferrero's "Er vi syge?" from 1893: literature may contain many a story about illness, but society, and the younger generation, in particular, is as healthy as can be.

The medicalized criticism of Henrik Dedichen takes place in a different context, by integrating literature into popularized scientific texts on medicine and psychiatry. Dedichen published widely on cultural topics as well as medicine in books and the daily press. His book *Paa begge sider af sindssygdommens grænse* (On Both Sides of the Border of Mental Illness) (1898) discusses the complicated borderland between mental health and illness. Dedichen makes extensive use of case studies from his practice as an asylum doctor at the state-owned psychiatric hospitals Gaustad and Rotvold, and an entire chapter is devoted to patients' literary productions. A manifesto written by the anonymous patient A.A., outlining his worldview in over 200 pages, is thoroughly analyzed. Dedichen calls attention to how the work oscillates between reasonable logic and paranoid confusion: A. A. copied or paraphrased text from journal articles and mixed them with his life story, poetry, and philosophical and cosmogenic conclusions. Interestingly, Dedichen compares the manifest to contemporary literature, stating that

> *"such a mixture of a still not entirely insane, although twisted, thinking and pretty natural reasoning is not seldom found in modern literature and is, in my opinion, undoubtedly evidence for spiritual abnormity"* (1898: 169, my translation).

In this manner, patient text (A.A.s manifest), patient story (Dedichen's narrative of A.A.'s life and illness), and literary text are confounded.

Dedichen goes on to comment on particular authors. While conceding that an author's mental health cannot be judged by reading his or her books alone, he still finds that many contemporary authors show worrying tendencies. He finds the depictions of mental illness in their books to be too vivid, too authentic, not to be have been experienced and thus connects lived experience with fictional representation (1898: 169). He exemplifies this by commenting on the works of the Swedish author August Strindberg. Strindberg describes mental illness in such a way that he must have suffered from it himself. Dedichen concludes, if Strindberg's depictions are based on observation and not on experience, he is a man of science and not an author (ibid. 170). In a postscript, Dedichen notes that Strindberg has since been committed to an asylum, proof that Dedichen's textual diagnosis was precise.

Dedichen was familiar with the works of Max Nordau and criticized his analysis of literary degeneration in several of his own texts. As late as in 1906, in the article "Geniet en nevrose" (Genius as Neurosis), Dedichen laments that the concept of degeneration is widely misunderstood and misused. Echoing Scharffenberg, Dedichen argues that the exaggerated notions of quick generational decline *"will* *never be science, even if the theory is ever so popular and can be found both with Max Nordau and in the newspapers*" (1906: 108, my translation). Again, it is not the reality of the phenomenon that is being questioned: Dedichen admits that genius may be related to disease and deviancy. He contests, however, that all art is therefore caused by degeneration, and that literature and art may be understood as symptoms of cultural decay (Dedichen, 1906: 113).

Both Scharffenberg and Dedichen used textual strategies aligning them with an already established medicalized literary criticism. Their critical practices contributed to an illness narrative connected with the *fin de siècle*, in which both individuals and society were understood through medical analogies. Like Collin and Scharffenberg, Dedichen practices a 'medicalized' or 'scientific' literary criticism differing from that of Nordau in conclusion but not in principle. They all perform variants of literary diagnostics and use medicalized language to examine the influence of literature on society. As intellectuals with one leg in their professional field and one in the public sphere (cf. Bourdieu 1992), Scharffenberg and Dedichen participated in the public debate from a point of authority. As we have seen, these 'medics-as-critics' often bring nuance to the established debate on literature and illness, but they never challenge the principles on which the broader medicalized literary criticism was built. Their critical practices must have contributed to the understanding of the many literary illness narratives and pathographies published in this period, as well as to the prevalence of illness narratives and a medicalized language in the critical domain itself.

These are only a few examples of what was a widespread critical practice in the decades surrounding the year 1900, which, being largely forgotten today, merits closer study. Within the medicalized literary criticism, literature and science became part of the metanarratives on illness in society and culture, often echoing the narratives of the literary works they departed from and criticized. Connected to these metanarratives are particular methods of reading literature and assessing the value of literature and medical science in a cultural context. This includes the establishment of a medicalized language in which to speak about the connections and influences surrounding the categories of author, text, reader, and context. Medicalized forms of criticism influenced both the literary and the medical fields. Scharffenberg and Dedichen develop and perform methodological readings that may have served to explore ways of reading and interpreting signs in a 'professional' or 'scientific' manner within emerging professions, notably psychiatry. The field of criticism, in its fusion of reading, interpreting, evaluating, and writing, partly overlapped with the institutional discourses and practices within the rising medical profession—anamneses and psychiatric notes, reports and evaluations. Within the practices of medicalized criticism, we see the contours of interdisciplinary questions we revisit even today: where and in what ways do literature and medicine meet, and with what consequence?

Notes

1. All translations from Norwegian to English are mine unless otherwise stated.
2. Guglielmo Ferrero's article was paraphrased and commented on in *Aftenpostens* regular column "Dagens Spørgsmaal i Udlandet," where it was named "Er verden et Daarehus?" (*Aftenposten* 1893.09.10) shortly after its original publication in the French *Revue des Revues* in 1893. Ferrero also became a regular contributor to the journal *Samtiden* after his text was published there.
3. *Aftenposten* 1893.09.10 and 1895.03.31.

References

Andersen, P. T. (1992). *Dekadanse i nordisk litteratur* 1880-1900. Oslo: Aschehoug

Buvik, P. (2003). Livskampen. Om Garborgs dekadanse-disputt med Christen Collin. *Tema*. <http://www.localmotives.com/hoved/¬tema/nr_6/Buvik.html>, 09.11.2015.

Bondevik, H. (2009). *Hysteri i Norge. Et sykdomsportrett*. Oslo: Unipub.

Bondevik, H. (2007). *Medisinens orden og hysteriets uorden. Hysteri i Norge* 1870-1915. Ph.d. avhandling ved Universitetet i Oslo, *Acta humaniora* no. 297. Oslo: Universitetet i Oslo.

Bondevik, H. (2005). Henrik Ibsen og hysteriet. *Edda* 4/05. (pp. 327-342).

Bondevik, H. & Stene-Johansen, K. (2011). *Sykdom som litteratur*. Oslo: Unipub

Bondevik, H., Madsen O.J., & Solbrække K.N. (2017). *Snart er vi alle pasienter. Medikalisering i Norden*. Oslo: Scandinavian Academic Press.

Bourdieu, P. (1992). *Les règles de l'art. Genèse et structure du champ littéraire*. Paris: Seuil.

Chamberlin, E., & Gilman, S. L. (eds.) (1985). *Degeneration. The Dark Side of Progress*. New York: Columbia University Press. https://doi.org/10.7312/cham90822

Collin, C. (1894). *Kunsten og Moralen. Bidrag til Kritik af Realismens Digtere og Kritikere*. København: Gyldendal.

Cohen, M. (1999). *The Sentimental Education of the Novel*, Princeton: Princeton University Press.

Dedichen, H. A. T. (1906). Geniet en nevrose. *Samtiden. Populært tidsskrift for litteratur og samfundsspørsgmaal. Syttende Aargang*. Gerhard Gran (ed.). (pp. 97-113). Kristiania: Aschehoug.

Dedichen, H. A. T. (1898). *Paa begge sider af sindssygdommens grænse. Studier af Henrik A. Th. Dedichen. Reservelæge ved Rotvold asyl*. Kristiania: Det norske Aktieforlag.

Felski, R. (2008). *Uses of Literature*. Oxford: Blackwell. https://doi.org/10.1002/9781444302790

Ferrero, G. (1893). Er vi syge?. *Samtiden Populært tidsskrift for litteratur og samfundsspørsgmaal. Andre Aargang*. Gerhard Gran (ed.). (pp. 361-367). Kristiania: Aschehoug

Furuseth, S. (2016). 1890-1905: Profesjonalisering av kritikken. In Sissel Furuseth, Jahn Hollhjen Thon og Eirik Vassenden (eds.) *Norsk litteraturkritikks historie* 1870-2010 (pp. 75-86). Oslo: Universitetsforlaget.

Hagen, E. B. (2013). *Livets overskudd. Bjørnstjerne Bjørnsons glemte kvaliteter*. Oslo: Gyldendal.

Johannisson, K. (2009). *Melankoliska rum. Om ångest, leda och sårbarhet i förfluten tid och nutid*. Stockholm: Bonnier.

Jurecic, A. (2012). *Illness as Narrative*. Pittsburgh: University of Pittsburg Press. https://doi.org/10.2307/j.ctt5hjr8p

Jørgensen, J. L. (2014). *Sygdomstegn. J.P. Jacobsen, Niels Lyhne og tuberkulose*. Odense: Syddansk Universitetsforlag.

Lie, J. (1893). *Niobe. Nutidsroman*. København: Gyldendal.

Nordau, M. (1993 [1892-1893]). *Degeneration*. Translated from the second edition, unknown translator. Lincoln og London: University of Nebraska Press.

Madsen, O. J. (2017). »Medikaliseringsbegrepets kolonisering av forskerverden«. *Snart er vi alle pasienter. Medikalisering i Norden*. H. Bondevik, O.J. Madsen & K. N. Solbrække (eds.). Pp. 25-62. Oslo: Scandinavian Academic Press.

Midbøe, H. (1966). *Dikteren og det primitive 3: Jonas Lies mesterskap*. Oslo: Gyldendal.

Morel, B-A. (1857). *Traité des dégénérescences physiques, intellectuelles et morales de l'espèce humaine et des causes qui produisent ces variétés maladives*. Paris: J.B. Baillière.

Pick, D. (1989). *Faces of Degeneration. A European Disorder*, c.1848-c.1918. Cambridge: Cambridge University Press. https://doi.org/10.1017/CBO9780511558573

Scharffenberg, J. (1894a). Literære kandestøberier. Part I. In: *Dagbladet* 1894.02.11. <https://urn.nb.no/URN:NBN:no-nb_digavis_dagbladet_null_null_18940211_26_41_1>, 30.04.2019.

Scharffenberg, J. (1894b). Literære kandestøberier. Part II. In: *Dagbladet* 1894.03.04. <https://urn.nb.no/URN:NBN:no-nb_digavis_dagbladet_null_null_18940304_26_62_1>, 30.04.2019.

Scharffenberg, J. (1894c). Literære kandestøberier. Part III. In: *Dagbladet* 1894.03.18. <https://urn.nb.no/URN:NBN:no-nb_digavis_dagbladet_null_null_18940318_26_76_1>, 30.04.2019

Søbye, E. (2010). *En mann fra forgagne århundrer. Overlege Johan Scharffenbergs liv og virke 1869-1965*. Oslo: Oktober.

Thon, J. H. (2016). Samtiden og konsolideringen av kritikkinstitusjonen på 1890-tallet.

Sontag, S. (2010 [1978]). *Sykdom som metafor. Et essay om holdninger til sykdom og død i vårt samfunn*. G. Schøning (transl.). Oslo: Bokklubben.

Vassenden, E. (2016) Kunsten, moralen og kritikken. Christen Collin og naturalismedebatten våren 1894. S. Furuseth, J. H. Thon, & E. Vassenden (eds.) *Norsk litteraturkritikks historie* 1870-2010 (pp.110-118). Oslo: Universitetsforlaget.

Vassenden, E. (2012). *Norsk vitalisme. Litteratur, ideologi og livsdyrking 1890-1940*. Oslo: Scandinavian Academic Press.

Warberg, S. (2016). *Den fødte forbryter. Diskursive brytninger i fremstillinger av kriminalitet og degenerasjon i norsk litteratur og offentlighet 1890-1910*. Ph.d. NTNU. < http://hdl.handle.net/11250/2423509>, 10.10.2018.

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The included outlaw

A study of the seclusion in Amalie Skram's Professor Hieronimus

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This article presents an analysis of Amalie Skram's 1895 novel Professor Hieronimus, with an emphasis on the seclusion aspect of this patient narrative. In the article, I give a close reading of the novel where I make use of insights from theorists from different disciplines, such as Shoshana Felman, Erving Goffman and Giorgio Agamben. The intent of the analysis, is to show how Skram manages to expose the rigid social categories that characterize the total institution in which the novel's protagonist, Else Kant, claims to be wrongfully lodged. Through a critical assessment of the institutional hierarchy, both social and medical, Amalie Skram makes her novel well-suited for the type of interdisciplinary readings that in the last couples of decades have expanded and become more accessible, thanks in part to the emergence of the field of literature and medicine. This development grants us the opportunity to revisit the works of the Scandinavian literary canon with a fresh theoretical perspective, where fiction bears the potential to articulate aspects of the patient experience that has yet to be encapsulated by theory. This article shows how this phenomenon includes studies that are not limited to this interdisciplinary field alone, meaning that a complex patient narrative such as Skram's Professor Hieronimus is accessible to a broader theoretical material as well.

The included outlaw: A study of the seclusion in Amalie Skram's Professor Hieronimus

If we were to establish a Scandinavian canon of illness literature, Amalie Skram's novel *Professor Hieronimus* from 1895 would be a cornerstone. Yet, as its only mentioned diagnosis, madness, is debated and disputed in the novel and the protagonist keeps insisting that she is wrongfully hospitalized, many of the categories and descriptions found in the theoretical literature regarding illness stories and patient narratives are challenged. In this article, I will explore how Skram's novel articulates vital aspects of the patient experience that will be addressed by theorists and philosophers at significantly later points in history, both within and outside the interdisciplinary field of literature and medicine. The intent of the study is to show, how Skram's novel manages to expose the hollowness of the strict social and medical categories characterizing the institution portrayed in her novel.

Professor Hieronimus is the first part of a duology that continues with *På St. Jørgen*, published the same year as its precursor. Both novels describe the experience of being kept as a patient against one's will, where communication and language fall short within the structures of an institutionalized health system. *Professor Hieronimus*, which will be analyzed in this article, aptly exemplifies the significance of the *seclusion*. This is often mentioned as a vital part of the patient experience without being subject to further elaboration, and it is in part this, I will try to remedy in my reading of Skram's novel. In addition, I will include insights on isolation as a phenomenon of thinkers from outside the field of literature and medicine. Overall, this article gives an examination of seclusion and isolation from different theoretical angles, as well as a close reading of the animalistic imagery in the novel. In this, I will discuss how Skram exposes the total institution's hierarchy and categories in a way that makes her novel accessible to analytical approaches across disciplines.

Professor Hieronimus

Professor Hieronimus' protagonist, Else Kant, is in a state of crisis amongst other things due to the pressure of functioning as a mother, a wife and an artist simultaneously. She is sleep-deprived, unable to work, and experiences hallucinations and suicidal thoughts. She finally agrees to commit herself under the care of the well-known Professor Hieronimus whose dissertation she has read with interest.

However, as soon as she has crossed the threshold of the asylum she is denied access to her belongings and she is prohibited from contacting her family or anyone else outside the hospital. The meeting with the professor is deeply disappointing to her and she experiences the stay as imprisonment, where she is isolated, stripped of her rights and dignity, and accused of being insane. At the end of the novel, she is transferred to a so-called insane asylum, and as she leaves, she promises the professor that the minute she is out of the institution he will be held accountable for his mistreatment of her and her fellow patients.

The novel caused quite a stir at the time of its publication, in part due to the fact that it was read as an autobiographical account of the some-two months that Skram herself had spent in hospitalization in 1894. First in the municipal hospital in Copenhagen, and later in the insane asylum Sct. Hans. In the debate following the publication, other (female) patients shared their accounts of being under the care of Knud Pontoppidan, who was widely understood to be the biographical model for Professor Hieronimus. After the debacle, he published a form of apologia, *6te Afdelings Jammersminde* (1897), and eventually resigned from his position.[1]

Seclusion is an important keyword in Skram's novel, which connects it to the theoretical literature concerning (alleged) madness, illness, and hospitalization where this experience is often accentuated. More often than not, scholars will emphasize that being hospitalized, not only means a break from usual routines or company, but also, that entering an institution includes isolation so profound that it changes the patient's world, often by her entering a different one. Skram is a pioneer in addressing such seclusion in literary form, and in Denmark alone, we can see clear literary descendants both in writers from Skram's time and at later points in literary history. Helga Johansen, for example, wrote the novel *Hinsides* in 1900 and the text possesses clear parallels to *Professor Hieronimus* (it was published under the pseudonym Hanna Jöel). A later example is the more famous Tove Ditlevsen's novel *Ansigterne* from 1968. Both address the medical institution as a secluded otherworld and they use this other world to explore the connection between "madness" and artistic creation, both writers were even hospitalized in the same institutions as Skram.

To mention a few examples of the emphasis on seclusion in theory related to literature and medicine: *In Litterära besvär,* Katarina Bernhardsson refers to a patient describing his hospital room as a *world within a world*, or rather a world outside the ordinary world (Bernhardsson, 2010: 11). Anne Hunsaker Hawkins' influential *Reconstructing illness,* describes how *"the individual – now a patient – crosses a threshold into a strange otherworld of rituals and ordeals, an unknown territory […].*

[W]hether they want to or not, the sick become denizens of a strange land" (Hawkins, 1999: 78). Hilde Bondevik and Knut Stene-Johansen describe, how the isolation connected to the hospitalization in literature provides us with the opportunity to view the medical institution as a laboratory for human experience (Bondevik and Stene-Johansen, 2011: 137-139). In *Madness and civilization* (L'histoire de la folie à l'âge classique), Michel Foucault famously outlines how we have condemned different types of insanity to exist *outside* society where the *stultifera navis*, the 'ship of fools' is replaced by a hospital that locks madness in (or out), which he labels 'the great confinement' (Foucault, 2008: 30-32). Equally famous in regards to illness literature is Susan Sontag's classic *Illness as a metaphor*, where illness is understood as a *kingdom* of its own and the asylum as a *world* of its own: "*Once put away, the patient enters a duplicate world with special rules*" (Sontag, 1978: 36).

Madness as 'outside culture'

In *Writing and madness*, Shoshana Felman, building on Foucault, states that our society builds walls around mental institutions "*to keep apart the inside and the outside of a culture, to separate between reason and unreason and to keep apart the other against whose apartness society asserts its sameness and redefines itself as sane*" (Felman, 2003: 5). She also writes, that "[*m*]*adness usually occupies a position of* exclusion*; it is the* outside *of a culture*" (Felman, 2003: 13). In her book, Felman describes madness as "*the most subversive of all cultural questions*", and states that the phenomenon causes different theoretical disciplines to converge (Felman, 2003: 12). Felman's examples of the disciplines, whose boundaries are subverted by the question of madness include sociology and philosophy (and history, psychology, literature and psychiatry). This statement which will be put to use in this article, as the patient experience described in *Professor Hieronimus* will be analyzed with help from respectively a philosopher and a sociologist, namely Agamben and Goffman.

Felman asserts, that madness only represents the outside of a culture, and thus a position of exclusion, as long as it is not a commonplace. When madness becomes inflated or overly accessible, the phenomenon starts to represent, according to her, "*a position of* inclusion *and becomes the* inside *of a culture*" (Felman, 2003: 13). The perceived madness in *Professor Hieronimus* becomes for us the inside of a culture for several reasons. For one, because the question of madness within the walls of the hospital is continuously debated and changes throughout the novel: Kant's initial reluctance to share even the same floor as 'madwomen' develops into a form of solidarity. As she actually feels somewhat better and becomes more mentally stable after a time spent in the institution, the question of her insanity from the doctor's point of view is less up for debate than before and his belief that she is insane becomes stronger. In addition to this, as Kant exposes her doctor as no less abnormal or irrational than herself, she makes the 'madness' category somewhat fluent and thus turns what is initially an outside culture into an inside one.

Asylums and Homo sacer

Both Giorgio Agamben's *Homo sacer* and Erving Goffman's *Asylums* examines forms of seclusion with vastly different approaches. Agamben treats his study as a sort of macro theory on modern society and it is especially the chapter titled "The ban and the wolf" that can provide us with increased comprehension of the isolation in the novel. His idea of 'bare life' will also be briefly made use of, as it directly addresses the experience of being 'banned' from a political or social form of life, which is an effective (if drastic) description of the patient experience formulated in Skram's novel. 'Bare life' as understood by Agamben, means that the banned citizen operates *"in an inclusive exclusion as the referent of the sovereign decision"* (Agamben, 1995: 85). Especially, the image of animality in relation to madness, an ancient combination, becomes apparent in Skram's novel when read in light of Agamben's discussion of the werewolf as an image of the citizen being both banned and included at the same time. He does not, then, focus on the patient experience, but rather on the seclusion from society understood as a ban. He shows how a citizen forced out of a social or political sphere remains deeply connected to the powers that have put her on the outside.

Goffman's work, on the other hand, is explicitly dedicated to the experience of belonging to an institution and provides us with a thorough description of the concept of social control within a secluded medical institution. His work, therefore, becomes a fitting example of how predecessors to theory can be found in fiction that connotes Felman's assertion, that literature has played an important role in developing our culture's receptiveness of 'madness' (Felman, 2003: 14-15). Goffman adds to the common depiction of the medical institution as a separate world, as he describes it as *"something of a world for [its members]"* (Goffman, 2009: 4.). However, unlike many others making use of this figure of speech when describing the patient experience, Goffman elaborates on the subject. These two theorists, Agamben and Goffman, will ideally complement each other's insights with their exceedingly different approaches to different types of seclusion, which in this analysis will supplement a few analyses of Skram's novel and mentions of the isolation aspect of the patient experience as found in the field of literature and medicine.

The hospital as a total institution

In *Asylums. Essays on the social situation of mental patients and other inmates,* Goffman explores institutions characterized by exactly the type of seclusion described in Skram's novel. The *total institution* is a key term in Goffman's study of the treatment of mental patients and other inmates in Western history. The kind of institutions that qualify as total are described as such:

> "*Their encompassing or total character is symbolized by the barrier to social intercourse with the outside and to departure that is often built right into the physical plant, such as locked doors, high walls, barbed wire, cliffs, water, forests or moors*" (Goffman, 2009: 4).

Goffman goes on to describe the different types of institutions that fit this characterization, which he divides into separate groups.[2] The hospital where Kant becomes a patient can be said to belong to a group described as "*places established to care for persons felt to be both incapable of looking after themselves and a threat to the community*". Goffman mentions mental hospitals as an example of such an institution (Goffman, 2009: 4). The degree of seclusion and isolation that Kant faces with her entrance to the hospital surprises her but it soon becomes clear that she is deemed both incapable of looking after herself and a threat to the social order, thus, a degree of isolation is thought to be a fitting treatment for her, despite her protests

Goffman's insights derive from a study of a large patient institution in the US in the 1950s (Goffman, 2009: vii) and can for that reason not without hesitation be used to gain a fully nuanced understanding of the hospitalization and patient experience portrayed in Skram's novel, which is set in a different country in a different era. Yet, his descriptions of the total institution comply with Kant's accounts: The social control, the communication difficulties between patients and staffers (where the latter are often understood as condescending and highhanded) and the patient's experience of lost integrity. Most of the specific examples mentioned in Goffman's analysis (the denied access to one's belongings, the opening of the patient's mail, the lost ability to control routines, diet and sleep patterns) all occur in Skram's patient narrative.

Petter Aaslestad reminds us in *Pasienten som tekst*, with a nod to Foucault, that how we view madness, mental illness and different forms of treatment of such cases, changes through the eras (Aaslestad, 2007: 21). When reading Skram in light of the theory that explores seclusion, this must be considered; In arguing that we should (re-)read Skram's novel today, it is not from the assumption that being hospitalized today is interchangeable with the patient experience as described in a work of fiction from the 1890s. Skram nonetheless anticipates aspects of the patient experience that would, later on, be addressed and expressed in the theoretical literature. Thus, she provides us with a literary-aesthetic knowledge that can later be supplied by an epistemic one even though the context of the mental hospital is different in Skram's context than in Goffman's.

More often than not, works that set out to provide an overview of the psychiatric history of Denmark mention the case of Amalie Skram, how the novels processing her hospitalization caused other (previous) patients to contribute their stories as well, and how this eventually led to Knud Pontoppidan resigning from his position (see for example Kragh, 2008: 148, or Nielsen, 2018: 22). Kragh stresses, that at the time of Skram's hospitalization there were no truly effective treatment methods in Danish psychiatry for 'madness' (Kragh, 2008: 148-149), and Petter Aaslestad points out that there were no 'insanity laws' in Denmark at the time (Aaslestad: 2009). There were, however, extensive discussions regarding the issue and this could be part of the reason why Skram's two novels made such a debacle at the time of their publishing, paired with the fact that Knud Pontoppidan was a well-known and reputable public figure.

Thus, Skram writes herself into not only the Scandinavian history of literature but of medicine as well. Readers have for good reasons assumed that the historical model for the hospital portrayed in *Professor Hieronimus* is the municipal hospital in Copenhagen, where Skram was briefly hospitalized in 1894, before being transferred against her will to Sct. Hans insane asylum. We, therefore, find pieces of Danish medical and psychiatric history in the novel. For example, Jens-Emil Nielsen discusses, how several institutions sat out to copy the structure of the Copenhagen institution (Nielsen, 2018: 12): There were about twenty cells for delirious or 'severely insane' patients, but under Knud Pontoppidan's leadership the hospital developed into an institution where patients could be hospitalized before they potentially were transferred to Sct. Hans (Nielsen, 2018: 12), thus becoming outlaws on a larger scale than before.

In an otherwise insightful reading of Skram's asylum novels from 1992, *Sammenbrudd og gjennombrudd. Amalie Skrams romaner om ekteskap og sinnssykdom*, Irene Engelstad writes, that it is rare for a psychiatric patient to feel the need to share the experiences afterwards. She suggests, that when Skram does this anyway it can be related to masochistic destructive tendencies which researchers like Pil Dahlerup have argued is widespread especially amongst female naturalists (Engelstad, 1992: 175-176, Dahlerup, 1975: 32-33). Rather than seeing Skram's ability to transform her experiences into a groundbreaking observation of the rigid social categories of the medical institution as an expression of self-destructive tendencies typical of female artists from her era, new theoretical developments enable us to gain a fuller understanding of Skram as a pioneer in the patient narrative tradition. This is not made less pertinent, by the fact that today a great many former patients feel a need to share their experience of hospitalization after they have left the institutions. Regardless, Skram's protagonist becomes both an observer of the hierarchy as well as somewhat of an outlaw in the total institution. This calls for a closer examination of what this last part entails.

The patient as homo sacer

Agamben's study of the banned citizen can provide us with a better understanding of the patient as an outlaw, a supplement to our understanding of her as a participant in a total institution. Kant arrives at the hospital with the perception that she has *rights* as a patient but gradually realizes that this is not the case. "*The law is on the side of the normal*", as Virginia Woolf states in her essay "*On being ill*" (Woolf, 2002: 23). Upon leaving the institution at the end of the novel, Kant makes a final attempt of negotiation with a doctor regarding her state as an outlaw:

> "– *Does a man have the legal right to lock up his wife in an insane asylum against her will, as soon as he and a doctor declares her insane?*
> – *Yes. And vice versa.*
> – *Then abuse can easily occur, said Else.*
> – *Yes, and that seems to happen quite a bit, too, was the resident doctor's re sponse.*
> – *And I have no rights? I'm not allowed to speak to an attorney or a friend?*
> – *No, not when You're here. And the chief physician at "St. Jørgen" can keep You there for years if he wants to – there came a smile of triumph in the*

> *resident doctor's eyes, as if of enjoyment over the power possessed by doctors."* (Skram, 1978: 164-165)[3]

The forced isolation and the loss of her rights as a patient makes Agamben's study a fitting supplement for a better understanding of the seclusion in the case of Kant. It revolves around the *homo sacer*, a figure from Roman law that can legally be killed, but not sacrificed, and Agamben argues that this figure communicates relevant aspects to understand the sovereign power over individuals in our modern society. The banned citizen lives outside the law because he has no protection from it. But because he is banned, he is still fundamentally attached to the law. The *homo sacer* is, in other words, included *"solely in the form of its exclusion"* (Agamben, 1995: 8) which is a trait the figure can be said to share with the involuntary hospitalized.

Agamben discusses the modern *homo sacer* figure in its most extreme form, as seen in prison and concentration camps, and his examples are no doubt more 'severe' than how we today would consider a well-functioning hospital in Denmark in the 1890s. However, the hospital is referred to by the patients of the novel as a prison. The parallel between the hospital and the prison in *Professor Hieronimus* is first made in the form of a simile as Kant expresses her reluctance to enter the institution as her husband drops her off: *"– I don't want to go in. It's locked, as if it were a prison"* (Skram, 1978: 23). Later in the novel, the similarity has evolved into a metaphor:

> *"she recollected with horror the first evening, when she relatively audacious had come here without knowing that she for an indefinite period was entering a prison and were to be treated as a culprit, to whom not even those closest to her would gain access"* (Skram, 1978: 74).

Finally, upon leaving the institution and on her way to the insane asylum the very last sentence in the novel reads: *"And finally she was heading to her new prison"* (Skram, 1978: 166). Goffman specifies that *"what is prison-like about prisons is found in institutions whose members have broken no laws"* (Goffman, 2009: xxi), a statement which rings true in Kant's descriptions of the asylum.

In *Homo sacer*, Agamben describes a dividing of life into two different parts initially done by the Greeks: 'Life' could either mean *bios* or *zoé*, where the former points to social life integrated in a society (also referred to as 'political life'), and the latter is 'the bare life', which is the life excluded from society, the life that we share with *animals*. *Bios*, then, is a qualified form of life, while *zoé* is the natural, reproductive life (Agamben, 1995: 109). The *homo sacer* figure is someone who has been reduced from the political/social to the bare life and is, therefore, excluded from society whilst remaining connected to it. Kant is a seemingly successful artist and her experience of hospitalization can be described as a reduction from a more social/political sphere to one closer to the animal sphere. This reminds us of Felman's divide between the inside and the outside of a culture, and it brings us to the animalistic descriptions in the novel.

The social animality of the institution

Kant is at first deeply uncomfortable with being placed in the same sphere as patients she considers to be far 'madder' than herself. The delirious patients' persistent screams in the night are continuously described as cries as from wild animals and serve in the beginning as proof for Kant that she does not belong in such surroundings. At a later point in the novel, when she to a larger degree has accepted her temporary fate as a patient, belonging to a wing of the institution where her voice is not heard and her opinions are not considered, she has the following reflection: "*Yes, yes, yes, she was taken care of and looked after like a strange animal*" (Skram, 1978: 161). The numerous juxtapositions of the patients and animals serve as a possible argument that they are reduced to a form of bare life under Professor Hieronimus' care. The fact that Kant sees them this way as well connects her to the oppressive rulers and complicates the medical hierarchy.

In the beginning, Kant's main issue is that the delirious patients that live one floor beneath her keep her up at night with their animal-like screams: "*Then began the horrors from the previous night. The same [...] inhuman roars, pervading bawls and swears from the delirists downstairs*" (Skram, 1978: 44). At a slightly later point in the novel, her fellow patients are more explicitly made animal: "*Suddenly she heard a bowl that had nothing human to it [...]. It was like a howling from mad dogs, like bellows from bulls, like cockcrow, like owl's hoots*" (Skram, 1978: 90). The screams also remind Kant of lions, tigers and wolves (Skram, 1978: 93).

The threshold between the human and the animal life is particularly fitting in the case of *homo sacer* in the section of the study titled "*The ban and the wolf*", where Agamben explicitly makes use of animal imagery: The figure of the *werewolf* is used to describe the outlaw in Germanic and Scandinavian(!) societies: "*a monstrous hybrid of human and animal, divided between the forest and the city – the werewolf*

– is […] in its origin the figure of the man who has been banned from the city" (Agamben, 1995: 105). The outlaw is not seen *completely* as an animal but exists in a threshold state between the two spheres, in a *"zone of indistinction between the human and the animal"* (1995: 106). The outlaw is, thus, both excluded from and included in society at the same time: *"The life of the bandit is the life of the […] werewolf, who is precisely* neither man nor beast, *and who dwells paradoxically within both while belonging to neither"* (Agamben, 1995: 105).

As Kant's initial attempts to reason with the nurses and the doctors fail, and she is not permitted to leave the institution, communicate with anyone or gain access to her things her view of the asylum's animality gradually changes. The sounds from the other patients start to become bearable and then something actually soothing for Kant as her hospitalization progresses and she to an increasing degree identifies with the patients of the asylum: *"Then sounded cries as from wild animals. Else stiffened with fear for a moment, but then she knew it was the delirists downstairs, and something like relief ran through her. Thank God for the delirists!"* (Skram, 1978: 110). As shown by amongst others Petter Aaslestad (2009) and Christine Hamm (2000: 81-82), Kant becomes part of the asylum's structure and hierarchy, and to a certain degree accepts its laws, despite always insisting that she does not belong there, and one of the indicators of this development is that she starts to accept and even identify with her fellow patients' animalistic ways of protest.

A final instance of animals as an image that connects Kant to the confined world of the asylum, is the hallucinations she experiences at the very beginning of the novel before she agrees to her hospitalization. After several sleepless nights and a severe cough, she sees a herd of horses entering her bedroom door and it becomes clear that this is a recurring vision for her. The horses are beautiful but ominous, lifeless and without eyes, and they disappear the moment her husband, Knut, enters the room. Her profound amazement over the fact that he cannot see the horses makes him plead for his wife to seek medical help. A previous analysis of this motif, made by Engelstad in 1992, has focused on the fact that the horses lack eyes. Engelstad reads this in light of Else's other visions and hallucinations where this lack is a recurring trait and she connects this to Kant's artistic crisis, as she fears that she has lost her artistic vision (Engelstad, 1992: 194-195). In our context, however, it seems more pertinent to view the herd in light of the other animalistic imagery in the novel. The hallucination could initially easily serve as a foreshadowing of Kant's transition to an animal-like sphere. Conspicuously enough, after she has actually spent some time in the confined world of Hieronimus' asylum, the hallucination that implied that she initially belonged there, vanishes: *"The brown herd of horses? Where had it gone? Not once had she seen it here"* (Skram, 1978: 71).

"[W]hen entrance is voluntary", Goffman writes, *"the recruit has already partially withdrawn from his homeworld; what is cleanly severed by the institution is something that had already started to decay"* (Goffman, 2009: 14). A crucial detail in Kant's case, is that she enters the institution in question voluntarily albeit reluctantly. Therefore, there is no clear-cut divide to be found between a normal, domestic sphere where she is well adjusted and content and a radically different animalistic sphere to which she does not belong. The herd of horses that appears when Kant is at home and ceases to exist when she is hospitalized emphasizes her as a *border case.* Despite the initial need to separate herself from the 'crazier' patients, Goffman might describe this as *"being contaminated by contact with undesirable fellow inmates"* (Goffman, 2009: 29), Kant gradually starts to think of herself as an ally to her fellow patients. At the same time, her praise of the delirists can be read as gratitude of her placement *above* them in the institution's hierarchy and structure. Either way, Kant exposes and evades the institution's established categories.

In a confrontation with the professor, Kant asks rhetorically if he will not trade beds with her for a night so as to see what it is like being kept in a cell and as he replies she has the following reflection: *"No-o, he said, and it sounded like a horse's whinnying"* (Skram, 1978: 69); this seems critical in our context. Shortly after, Kant provokes the professor into losing his temper by constantly criticizing his methods. With a stroke of involuntary comedy, the professor screams that Kant is unable to control herself and that he had thought of moving her but that she can now stay where she is:

> *"Hieronimus' colourless face had turned grey as chalk. He lifted himself up to his toes and put his heels against the floor. – What You need most of all is to learn self-restraint! Your illness is that you cannot restrain yourself. I had planned on moving You – he smacked his one hand's tiny, plebeianly formed fingers against the other's inner palm and almost screamed: – But now You can stay where You are! and off he went out of the cell"* (Skram, 1978: 70).

First this too, is addressed by Goffman, who claims: *"To defend his own professional role and the institution that hires him, the psychiatrist is under pressure to respond by treating […] outpourings not as […] usable statements of information but rather as signs of the illness itself"* (Goffman, 2009: 367). Second, as Unni Langås has shown in her reading of Skram's novel, this sequence reveals that the professor possesses the same traits that he accuses his patient of, namely a lack of self-restraint. His criteria for ‘madness’, then, is not something that separates the two as doctor and patient but something that connects them (Langås, 2004: 219). The connotation of a horse’s neighing in the distance right before the professor’s lack of self-control becomes visible to us, works as a possible elaboration of Langås’ point.

On the one hand, the association to a horse places the professor in the same sphere as his patients, the animal-like sphere, and this can be seen as a foreshadowing of the imminent revealing of him as equally irrational, subjective and temperamental as Kant. On the other hand, the animal in question is not to be treated as a coincidence: Horses are not mentioned as one of the animals the uncontrolled patients remind Kant of as they scream in the night (they are affiliated with wild animals and dogs, owls, oxen and roosters). The neighing connotates the herd of horses that Kant hallucinates at the beginning of the novel that disappears as she becomes integrated into the institution’s social structure. This detail suggests, that Kant and the professor both reveal an affiliation to an animal-like sphere, although on a somewhat higher level than the patients that have no other mode of protest or self-expression than persistent nocturnal screams. And still, there is a dignity affiliated with Kant’s hallucinated horses that disappears with the professor’s distant neighing. Either way, as a reminder of Felman’s previously mentioned insights on madness as the inside of a culture when becoming commonplace, we can say that Kant in these sequences exposes the categories of the rigid asylum structure as arbitrary.

Partial animality, total institution

Goffman describes the total institution as a “social hybrid”, part community and part formal organization (Goffman, 2009: 12). With this in mind, we can note that Else Kant’s gradual alliance with the secluded sphere does *not* represent an exclusion from social life as one might have expected when reading *Professor Hieronimus* in light of *Homo sacer*. In her transition to and acceptance of her affiliation with the ‘animal sphere’ of the asylum she gains a community and starts communicating better with both her fellow patients, the nurses, and even a doctor. She is also able to care for other patients, urging them to obey the nurses’ orders and restrain themselves. Kant’s gradual internalization in the structure of the mental institution is a complex matter and it is not something inherently good or bad. That depends on how we view this sort of compliance, brought forward by a hierarchal demand for acquiescence, which the novel was, understandably, read as a critique of. Skram's novel, thus, reminds us of Kant as a border case and the patient narrative as a fundamentally complex one.

In his influential work *The wounded storyteller* (1995), Arthur W. Frank states (with a reference to Howard Waitzkin):

> *"The ideological work of medicine is to get the patient to accept [a] diagnostic identity as appropriate and moral. When the patient accepts this identity, he aligns himself as subordinate in a power relation"* (Frank, 1995: 66).

This is yet another example of an interdisciplinary study affiliated with the field of literature and medicine addressing a phenomenon already formulated in Skram's novel and it is this effective social organization that enables a parallel between the hospital in *Professor Hieronimus* and Goffman's description of the total institution. The question of patient subordination is, however, slightly more complicated in Skram's case; as the novel invites us to view it in a meta-perspective. When this is considered, the novel in itself serves as proof that the professor is indeed (as promised by his patient at the end of the first novel) held accountable for his (mis) treatment of her. In this perspective, the internalization found in *Professor Hieronimus* can be understood as a gradual build-up to a more profound protest of the structures at play in regards to Else Kant's hospitalization.

Like Agamben's werewolf, Kant belongs neither fully to the sphere of normality, as is made evident when she fails to get her husband to see the herd of horses allegedly passing through their home, nor to the sphere of animality. As a patient, she inhabits a threshold existence. This is how Skram's protagonist, who is in a way on the outside of society and refused access to it, still remains deeply connected to the powers that have placed her there. Thus, *Professor Hieronimus* serves as a good starting point for a longer exploration about the significance of isolation in patient stories, all the while reminding us that no institution is so closed off from society that it does not bear the potential to communicate something about said society by way of examining what it isolates, condemns and excludes. On the contrary: The more closed off an institution is, the more reason to dissect its structures. This is what Skram enables in her novel. In making her protagonist a subversive observer of the medical institution, she creates a literary character deserving of the theoretical developments that were still far ahead at the time of her creation.

Notes

1 For details on how the novel complies with biographical circumstances, see for example Engelstad (1996), Hamm (2000), Aaslestad (2009) or Bondevik (2010).

2 Goffman establishes five rough groupings of total institutions: Institutions that are "*established to care for persons felt to be both incapable and harmless, […] places established to care for persons felt to be both incapable of looking after themselves and a threat to the community […]. A third type of total institution is organized to protect the community against what are felt to be intentional dangers to it […]. Fourth, there are institutions purportedly established the better to pursue some worklike task and justifying themselves only on these instrumental grounds […]. Finally, there are those establishments designed as retreats from the world even while often serving also as training stations for the religious*" (Goffman, 2009: 4-5).

3 Translations are mine.

References

Aaslestad, Petter (2009). »Amalie Skrams asylromaner revisited«. Edda 1/09, vol. 96. (2007). *Pasienten som tekst. Fortellerrollen i psykiatriske journaler Gaustad 1890-1990.* Oslo: Universitetsforlaget.

Agamben, Giorgio (1995). *Homo sacer. Sovereign power and bare life*. California: Stanford University Press.

Bernhardsson, Katarina (2010). *Litterära besvär. Skildringar av sjukdom i samtida svensk prosa*. Stockholm: Ellerströms.

Bondevik Hilde (2010). »Who's afraid of Amalie Skram? Hysteria and Rebellion in Amalie Skram's novels of Mental Hospitals« in Stene-Johansen, Knut and Frederik Tygstrup (ed.) *Illness in Context*. New York: Rodopi. https://doi.org/10.1155/2012/490647

Bondevik, Hilde and Knut Stene-Johansen (2011). *Sykdom som litteratur. 13 utvalgte diagnoser.* Oslo: Unipub.

Dahlerup, Pil (1975). »Den kvindelige naturalist«. *Vinduet* 2/75, vol. 29.

Ditlevsen, Tove (1968). *Ansigterne*. København: Steen Hasselbalch.

Engelstad, Irene (1992). *Sammenbrudd og gjennombrudd. Amalie Skrams romaner om ekteskap og sinnssykdom*. Oslo: Pax forlag.

Engelstad, Irene (1996). »Er det mulig å male livsangstens symbol? Amalie Skrams Professor Hieronimus og På St. Jørgen som kunstnerromaner« in Aasen, Elisabeth (ed.): *Amalie. Silkestrilen sin datter*. Bergen: Amalie Skram selskapet.

Felman, Shoshana (2003 [1985]). *Writing and madness* (Literature. Philosophy. Psychoanalysis). California: Stanford University Press.

Foucault, Michel (2008 [1961]). *Galskapens historie i opplysningens tidsalder*. Polen: Gyldendal Akademisk.

Frank, Arthur (2013 [1995]). *The wounded storyteller. Body, illness and ethics*. Chicago and London: The University of Chicago Press.

Goffman, Erving (2009[1961]). *Asylums. Essays on the social situation of mental patients and other inmates*. London: Transaction Publishers.

Hamm, Christine (2000). »Sannhet og sinnssykdom: En lesning av Amalie Skrams romaner Professor Hieronimus og Paa St. Jørgen« in Bøe, Yngvild (ed.): *Årbok 2000. 7. årgang*. Bergen: Amalie Skram selskapet.

Hawkins, Anne Hunsaker (1999). *Reconstructing illness. Studies in pathography*. Indiana: Purdue University Press.

Johansen, Helga 1900). *Hinsides. En psykologisk Redegjørelse*. København: Lehmann & Stages Forlag.

Kragh, Jesper Vaczy (2008). *Psykiatriens historie i Danmark*, København: Hans Reitzels forlag.

Langås, Unni (2004). *Kroppens betydning i norsk litteratur 1800-1900*. Bergen: Fagbokforlaget.

Nielsen, Jens-Emil (2018). *Mennesker på sindssygehospital. En krønike om Sct. Hans, Risskoc, Oringe, Viborg, Middelfart, Nykøbing S., Vedsted og Augustenborg*. København: Bogforlaget HER&NU.

Skram, Amalie (1978 [1895]). *Professor Hieronimus*. Oslo: Pax forlag.

Sontag, Susan (1991 [1978]). *Illness as Metaphor & AIDS and its Metaphors*. England: Penguin books.

Woolf, Virginia (2002). *On being ill*. Ashfield, Massachusetts: Paris Press.

Originalartikel

Chaos Narrative and Experientiality in the Graphic Memoir

The Case of Thomas H. Nøhr's Cirkus

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This article contributes to research on illness narratives. It revisits Arthur Frank's notion of the chaos narrative and argues in favour of supplementing it with the concept of tellability, and with Monika Fludernik and David Herman's postclassical narratological approaches to the definition of narrative that foreground experientiality and what it's like. Furthermore, it is argued that tellability is recuperated at the discourse level in literary representations of the chaos narrative. Frank argues, that the chaos narrative cannot be represented, but in this article, the case is made that literature can mimick the chaos. It is suggested, to label this particular chaos narrative: The mediated chaos narrative. This is demonstrated in a reading of Danish cartoonist Thomas H. Nøhr's graphic memoir entitled Cirkus, which chronicles his encounter with the Danish health care system after suffering from stress, depression and severe burnout. The graphic memoir can experiment with the affordances of its multimodality to support the focus on narrative experientiality and to draw attention to issues of social justice. To render the chaos of the experience, Nøhr examines how the affordances of graphic memoir enables one to experiment with narratological *building blocks such as the distinction between the narrating I and the experiencing I and with Gérard Genette's three categories of time: order, duration, and frequency.*

Illnesses pose a challenge for the construction of a narrative. Since Aristotle's *Poetics*, plot – understood as a sequence of events or actions with a teleologically and causally based thread from the beginning through the middle to the end – has been crucial to attempts at defining a narrative. It can be difficult, though, to understand one's life as a plot-driven narrative, when it is interrupted by illness. To account for different illness narratives, the sociologist Arthur Frank introduces three types of illness narratives in his seminal book T*he Wounded Storyteller*: the restitution narrative, the quest narrative, and the chaos narrative. The first subsection of the chapter on the chaos narrative is entitled "Chaos as Non-Plot" (Frank, 1995, 97).

In this article, I will revisit Frank's chaos narrative and couple it with alternative definitions of narrative from postclassical narratology, where the emphasis is less on plot and more on experientiality (in Monika Fludernik's terms) and what-it's-like (in David Herman's terms). Furthermore, I want to argue, that the particular genre of the graphic memoir (i.e. comics autobiography) is primed to meet the challenge chaos narratives pose to the very category of narrative. My empirical case for probing these issues will be *Cirkus* by Thomas H. Nøhr.[1] *Cirkus* is a graphic memoir about mental illness and about the Danish health care system. I will commence by introducing Nøhr's work. This enables me to interpret my empirical case *as* I broach and discuss the relevant theory. *Cirkus* depicts a chaos narrative and in doing so, the protagonist's experientiality is foregrounded. I will argue, that his alternative experience of time necessitates an experimental rendition of time experience. The affordances of the graphic memoir are well suited to represent and experiment with narratological categories of time and narrative situations.

Social Justice and Nøhr's Artistic Accounts of the Danish Health Care System

Cartoon artist Thomas H. Nøhr has written a number of cartoons – ranging from comic strips to (short) graphic memoirs – based on his personal experience with stress and his confrontation with the Danish welfare system. They were first published online, but they have since been published collectively in *Når jeg tegner…* (translation: *When I Draw...*) in 2017. In a comic strip, *Fun with my Brain*, which has six panels, an unseen interlocutor asks him how he is feeling. Nøhr never replies, but his reflections are captured in thought bubbles. He has pain in his stomach and back, he feels stress all the time, he has headaches and is concerned about his bad memory and he feels safe but isolated in his home. In the final panel, he reflects: "*I worry about politics and social injustice, but maybe I'm just hypersensitive?*" (Nøhr, 2007: 27).[2] The issue of social justice is often evident even at a titular level. One, for instance, is subtitled "*Fun and Games with the Rather Large Mesh Social Safety Net*" (37), while another subtitle goes "*An Allegorical Catharsis Journey Through the Mind of the Author + A Rollercoaster Ride Through the Public Sector Represented in Bright Colors*" (59).

Nøhr's autobiographical comics *Cirkus (Circus)*, *Hu hej, tiden flyver (Time Flies)*, and *Livets skyggeside (Outcast of Fortune)* were composed as "*the result of an acute necessity like a sudden nausea that could not be suppressed*" (quoted in Larsen 2015). They describe Nøhr's experience of severe stress, a condition that was allowed to exacerbate for way too long before he sought out help. In an interview in 2015, Nøhr explains, that his therapist is still trying to decipher the nature of his mental condition, but that he has stress, depression and severe burnout. He says that his state resembles post-traumatic stress disorder. On the one hand, Nøhr uses his comics to find a language that accurately depicts his mental state but they also chronicle and subjectively criticize the Danish welfare system. Nøhr explains, that when he finally asked the system for help, "*an entire year went by, before I was told that nothing had happened with my case, that I had been forgotten*" (quoted in Larsen 2015). The delays went on and on, and at one point he started composing the aforementioned graphic memoirs. Nøhr finally received disability pension in 2015. The interview I have quoted from was done a few months after that, and in it Nøhr describes his hopes (or lack thereof) for the future:

> "*I have given up all ambitions about ever doing anything again. I'm completely exhausted. I don't know if I'll ever get well again, and my shrink tells me that there are no guarantees that this mental burnout will get better. And since I'm numbed, I strangely enough can't feel whether this is a good or bad thing.*" (quoted in Larsen 2015)

Nøhr was interviewed again in 2017 after *Når jeg tegner…* was published. Here, he describes his condition and future again:

> *"Now I feel like a normal human being again. But I have no plans to return to drawing. My aim now is to do as little as possible, except for trying to lose the 70 kilos I gained during my ten years with stress and depression"* (quoted in Andreasen).

In this article, I am going to focus on *Cirkus*. *Cirkus* is a rather short graphic memoir, consisting of only 15 pages (front cover included). The story itself – or, if you will, the "plot" – is even shorter; it is told in the first six pages, and then it is subsequently repeated throughout the remaining pages of the memoir. I will summarize it in some detail, because it is rather brief and because doing so is relevant to my interpretation.

In the first panel, the protagonist visits a health care office and says: *"Hello – I'm broken – is this where I can get help?"* The front desk secretary replies: *"Absolutely."* He is told that he needs to go see his doctor in order to get a referral to a psychiatrist and that he subsequently must procure statements from both the doctor and the psychiatrist about his condition. The doctor swiftly concludes that he is not looking well and that he will give him the referral. At this point, the bureaucracy kicks in; he is told that the wait to get an appointment with a psychiatrist is six months. He waits six months, while his condition exacerbates. He then sees the psychiatrist once a month for six months, after which the psychiatrist concludes that: *"It is now abundantly clear – you need to receive a disability pension"* (which essentially puts you on social benefits for life). He eventually returns to the health care office, providing the secretary with the statements from the psychiatrist and the doctor. He is told to take a seat in the waiting room (this is quoted in figure 1). After an unspecified amount of time (it takes more than 4 months…), he goes back to the health care office, and at this point he is only able to utter one syllable: *"Help…"* The secretary, smiling friendly as ever, tells him that he has been assigned to a new caseworker and that the statements from the doctor and the psychiatrist are now out of date; he will need to get new ones.

It turns out to be the end of the plot because this brief sequence then repeats itself – to infinity, it is suggested. However, as the story repeats itself, numerous changes to the representation of the same events are made at the discourse level. In figure 2, you see the third and fourth time the events that I just detailed are repeated. In figure 3 – which quotes the pages right after figure 2 – we can no longer count how many times the protagonist has procured statements and had them rejected:

Figure 1: "Cirkus" in *Når jeg tegner…*, pp. 104-105.

Figure 2: "Cirkus" in Når jeg tegner…, pp. 108-109.

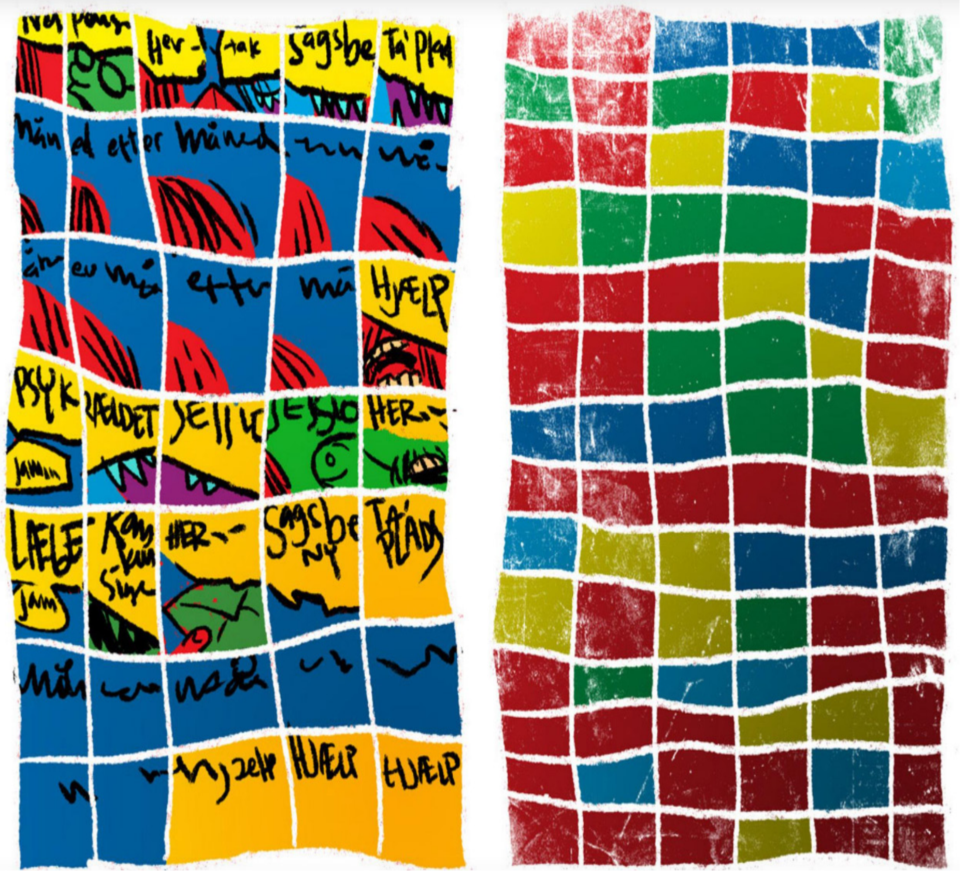

Figure 3: "Cirkus" in Når jeg tegner…, pp. 110-111.

Narrative and Illness: Losing the Plot

Illness is never planned for. Rather, it is part of life's contingency. As Schlomith Rimmon-Kenan has argued, "*[a]utobiographical writing about illness may be an attempt to control the uncontrollable, and hence it can become a battleground between the two competing principles [i.e. of the dictated order that hospitalization effects, and the inner disorder the patient feels]*" (Rimmon-Kenan, 2006: 244). Frank's first two types of illness narratives are exactly such attempts at mastery. Restitution narratives are about the restoration of health or the triumph of medicine. Frank paraphrases its storyline as follows: "'*Yesterday I was healthy, today I'm sick, but tomorrow I'll be healthy again*'" (Frank, 1995: 77). In quest narratives, patients "*meet suffering head-*

on; they accept illness and seek to use it. Illness is the occasion of a journey that becomes a quest," and the ill person believes *"that something is to be gained through the experience"* (Frank, 1995: 115). Chaos narratives are completely distinct from restitution and quest narratives. Frank states that:

> *"Chaos is the opposite of restitution: its plot imagines life never getting better. Stories are chaotic in their absence of narrative order. Events are told as the storyteller experiences life: without sequence or discernable causality."* (Frank, 1995: 97)

Hence, to Frank, chaos narratives might not even be narratives. Furthermore, chaos narratives are characterized by *"the syntactic structure of 'and then and then and then,'"* which results in a *"staccato pacing of words [that] pecks away at the reader"* (Frank, 1995: 99). In my summary of *Cirkus*, I deliberately tried to render the syntax of 'and then and then and then.' As a consequence *"chaos stories are hard to hear"* (Frank, 1995: 97). I find it profitable to supplement Frank's theory of chaos narrative with the concept of tellability to account for its unlistenable trait. Tellability is *"a quality that makes stories inherently worth telling, independently of their textualisation"* (Ryan, 2005: 589). The concept originates in oral storytelling, but it is often regarded as a criterion for narrativity.

When tellability is expanded to describe complex constructions in literary genres, it is necessary to invoke the narratological distinction between story and discourse. Story relates to *what* is told (independently of style and formal choices), whereas discourse designates *how* something is told. Tellability can be employed either as a concept that is independent of or characterized by the discourse level. Baroni writes that *"narrative interest might be proposed as a term for tellability when dealing with the interconnection between story and discourse"* (Baroni, 2011). It is precisely my argument that *Cirkus* has very low degrees of tellability at the story level, where the same non-event continually repeats itself, but that tellability is nonetheless recuperated at the discourse level. Any medium has a unique set of possibilities and limitations. Non-moving images, for instance, represent space in a frozen moment of time; movies show moving images; comics present sequences of non-moving images. Such possibilities and limitations constitute media affordances. Images, movies and comics obviously have many other affordances than the ones I just mentioned. Readers, I argue, take pleasure in engaging with Nøhr's experimentation with the affordances of the multimodality of the graphic memoir.

This, in turn, renders Nøhr's experience relevant, even as the story or plot is not in itself particularly tellable.

At this point, I would raise a critique of Frank's implicit definition of *narrative* as being too reliant on plot with its combination of telos and causality. In alternative definitions of narrative, plot structure is only one of the defining features. I want to single out two of these, which are related; namely, Fludernik's concept of experientiality and Herman's prototypical approach. Fludernik writes, that a personal narrative is a narrative *"not because it tells a story, but because the story that it tells is reportable,"* and, consequently, *"tellability and point of the story dialectically constitute each other"* (Fludernik, 1996: 70). In general, however, what endows something with the quality of narrativity is what she terms experientiality. Experientiality is defined as *"the quasi-mimetic evocation of 'real-life experience'"* (Fludernik, 1996: 12). Fludernik argues, that all narratives rely on the activation of cognitive frames and schemata that humans rely on in their actual lives. Experientiality, in Fludernik's argument, is much more essential to narrativity than plot:

> *"In my model there can, therefore, be narratives without plot, but there cannot be any narratives without a human (anthropomorphic) experiencer of some sort at some narrative level."* (Fludernik, 1996: 13)

Fludernik even goes to the extreme of claiming that *"[m]erely plot-oriented narratives are [...] argued to represent a zero degree of narrativity even though they are traditionally endowed with proto-typical narrativity"* (Fludernik, 1996: 13). While I recognize the fecundity in foregrounding human-like experience as a previously neglected and essential element in all narratives, I do not find the bold claim about plot to be productive. In defining what makes something a narrative, I would lean more towards David Herman's prototypical approach. According to Herman, prototypical narratives are constituted through four basic elements (Herman, 2009: 9): situatedness (the idea that a representation is situated in a specific discourse context or occasion for telling), event sequencing (the notion that interpreters draw inferences about a structured time-course of particularized events), worldmaking/world disruption (the events introduce a disruption or disequilibrium into a storyworld), and, finally, what it's like (i.e. the representation conveys the experience of living through the events represented; this is related to Fludernik's experientiality). In introducing four basic elements of narrative, Herman suggests that *"capturing what it's like to experience storyworld events constitutes a critical property of but not a sufficient condition for narrative"* (Herman, 2009: 139). A narrative that is constituted by all four basic elements – situatedness, event sequencing, worldmaking/world disruption, and what it's like – is a prototypical narrative, while narratives which only contain some of these are less prototypical; they have lower degrees of narrativity.

"What it's like," which Herman also calls the consciousness factor, is comparable to Fludernik's experientiality. In Herman's words, this element describes the fact that.

> "*[n]arrative representations convey the experience of living through storyworlds-in-flux, highlighting the pressure of events on real or imagined consciousnesses affected by the occurrences at issue.*" (Herman, 2009: 137; his emphasis).

Because of the somewhat arbitrary nature of life and illness and because experiencing illness can feel chaotic some illness narratives are difficult to represent. The raw story of Nøhr's *Cirkus* would appear to be almost impossible to make tellable. It was created and posted online when Nøhr was caught up in the bureaucracy, which delayed the arrival of the help he needed. It is not at all hopeful that health will be restored or that something is to be gained from the experience, so it is far removed from restitution and quest narratives. Rather, it suggests that waiting for the health care system to deliver help is like waiting for Godot in Samuel Beckett's absurdist theatre. The lack of narrative progression – marked by the 'and then and then and then' nature of the unfolding of the story – results in endless repetitions. Hence, *Cirkus* fits Frank's notion of the chaos narrative, but I would not call it an anti-narrative. It certainly is not a prototypical narrative, but it does fulfil certain criteria of narrativity. If we relate it to Herman's basic elements, it does have situatedness, as Nøhr posted it on Facebook, an occasion that was necessitated by his nausea. However, I would argue, that its relation to the element of event sequencing is volatile at best. Nøhr is trying to take action but everything is static at the story level. The element of worldmaking/world disruption is not introduced in prototypical fashion either. It seems like the stable storyworld (i.e. Nøhr's life) exists prior to the opening of this story. The disequilibrium or rupture then takes place in the very first panel, when he asks a professional for help. From then on, we just go round in circles. What it is like or experientiality, however, is foregrounded. This is a story about Nøhr's subjective experience of the disintegration of his mental health as the bureaucracy of the welfare state's health sector puts him under even more stress. Hence, *Cirkus* highlights experientiality in a way that draws attention to the drawbacks of the psychiatric system in place.

As mentioned, *Cirkus* gains the quality of tellability at the discourse level. It is not in any obvious way inherent in what is told. Rather, what makes it a good illness narrative is the experimentation with the affordances of the multimodality of comics, which I will address in the next section.

Why Comics? Reflection, Time, Silence

Comics artists have been composing autobiographies in comics since the 1970'ies. Graphic memoir seems to be the accepted label for this genre but, as Nancy Pedri notes, a number of alternative names have been proposed such as autographics, comic book memoir, autography, autographic memoir, graphic novel memoir, and autobiocomics (Pedri, 2013: 127). Since the turn of the millennium, graphic memoirs about illnesses have proliferated, and graphic medicine is a well-established academic research area within health humanities. What makes comics so well suited to represent the experience of illness autobiographically? I want to suggest at least three reasons, and in elaborating on the rationale behind them, I will continue the theoretical discussion in the previous section by testing the theory in an interpretation of Nøhr's *Cirkus*: 1.) its verbal-visual multimodality allows for play with the narratological distinction between the narrating I and the experiencing I, which relates to the question of whether one has mastery over one's story, 2.) the potential to experiment with narratological concepts of time, and 3.) the visual track can represent that, which cannot be put into words.

Narratology distinguishes between the narrating I and the experiencing I. The underlying premise is that first-person narrators are like people in real life. They can only report on something after it has taken place – not before or during the event. This means that the narrating I in literature (at least in theory) reports at a temporal distance from what was experienced. According to Dorrit Cohn, the relation between the narrating I and the experiencing I can be either dissonant or consonant. In dissonant narration, the narrator "*remains emphatically distanced from the consciousness he narrates,*" while consonant narration "*is mediated by a narrator who remains effaced*" (Cohn, 1983: 26). Graphic memoirs conventionally represent the narrating I as text in the captions. The experiencing I, then, inhabits the visual track as an avatar, i.e. a comics-style version of the autobiographical author. The discourse of the avatar/the experiencing I is represented as direct speech in speech bubbles or thought quotations in thought bubbles. The split between the narrating and experiencing I, hence, is foregrounded in graphic memoirs, which makes it primed for dissonant narration. Cohn writes that in dissonant self-narration, "*[t]he narrative process itself […] is emphatically conscious, deliberate, and intellectual*" (Cohn, 1983: 146). This would fit well with graphic memoirs about illness that function as restitution or quest narratives, but it goes counter to key features of the chaos narrative:

> "*When I refer below to the chaos narrative, I mean an anti-narrative of time without sequence, telling without mediation, and speaking about oneself without being fully able to reflect on oneself.*" (Frank, 1995, 98)

Nøhr's *Cirkus* does not employ dissonant narration. It is a curious case: on the one hand, it represents the overwhelming chaos imposed on Nøhr in his meeting with the health care system, and Nøhr mentions that he created it while engulfed in the chaos of the process; on the other hand, everything is meticulously arranged by Nøhr, so he has clearly been able to work artistically on giving form to the experience. *Cirkus mimicks* time without sequence, telling without mediation, and speaking about oneself without reflective distance, but clearly, there is mediation, and as mentioned the experience's tellability is recuperated at the discourse level. Nøhr mimics the lack of reflexive distance by employing consonant self-narration rather than dissonant self-narration. This might be termed the mediated chaos narrative. Nøhr does this in a visually conspicuous way by simply deleting – or, rather, leaving empty – all captions (save for a few time markers), i.e. the exact spot which the narrating I would otherwise inhabit. The potential to play with the narratological split between the narrating I and the experiencing I is one of the reasons why the graphic memoir is well suited to depict illnesses, as Jared Gardner has also commented on: "Comics autobiography from Green to Bechdel highlights that split and puts it to productive use, allowing the autographer to be both victim of the trauma and detached observer" (Gardner, 2008: 12). Nøhr's *Cirkus* is a chaos narrative that stresses the what it's like or experientiality of Nøhr's traumatizing ordeal and quest to get help. The position of the narrating I is deleted, but ambiguously some detached observer position is nonetheless indicated by the fact that the avatar is seen from the outside or drawn in the third person (like a character in a movie) and by Nøhr's overall construction of the discourse level.

Another reason why tellability is recuperated at the discourse level is Nøhr's experimentation with the comics medium's potential for time representation. Time is an important aspect of plot, and I have argued that the chaos narrative in general and Nøhr's Cirkus, in particular, lose the plot (if you will forgive the pun). So how and to what ends does Nøhr play with time categories? In *Narrative Discourse,* a seminal essay by the structuralist narratologist Gérard Genette, time is divided into three subcategories: order, duration, and frequency. The temporal order refers to the comparison between the order of the events at the story level with the order at the discourse level. The discourse's order is characterized by chronology or anachrony (the latter comes in many shapes). As mentioned, *Cirkus* is straightforwardly chronological, which contributed to the syntactic effect of 'and then and then and then'.

Frequency is more complex in *Cirkus*. Time-frequency is singulative when you narrate once what happened once. You can also narrate many times what happened only once. Finally, you can narrate one time what happened more than once (e.g.: Every day for 5 years I went to bed at 10). Genette calls the latter form for the iterative. Nøhr's avatar in *Cirkus* goes through the same motions so many times, and what he and the other characters say in dialogue is almost identical each time, so at a first glance, you might think that he is narrating many times what happened once. However, it is, in fact, singulative: "*the repetitions of the narrative simply correspond […] to the repetitions of the story*" (Genette, 1972: 115). This is, in fact, Nøhr's point: he should only need to get the statements once, but the system forces him to do essentially the same thing several times, rendering the singulative frequency circular. While the same thing happens over and over, the graphic world is gradually distorted, transforming into a surreal or nightmarish universe, before eventually being substituted for innumerable, non-figurative coloured panels. This immediately becomes obvious, when one compares figures 1-3. In figure 2, for instance, the secretary at the front office continues to speak to him in a friendly and accommodating way but visually the reader only sees a fragment of her face and she looks more and more daemonic (with sharp teeth and all). The fact that the panels become smaller as they grow in number accelerates the singulative (yet somehow repetitive) aspect of frequency. The panels gradually become less anthropomorphic (with fewer human-like figures and less speech) and, finally, they turn into non-figurative colours. At this point the materiality of the comics medium becomes visible. The shapes and colours in figure 3 are overdetermined. The panels and frames resemble both grids, prison bars, fences etc. As Nøhr's avatar disappears (his final word being the single-syllable word: "Help"), it is suggested that he has been chewed up by the system.

The accelerated frequency has an implication for the final time category. Duration addresses the narrative time (NT) compared to the story time (ST). ST refers to the time an event actually takes, whereas NT designates the time it (roughly) takes to narrate that same event. The narrative time is most often shorter than the story time. NT can to some degree be measured by the amount of text space an event takes up. Genette then distinguishes between the pause (e.g. a description where NT is infinitely greater than ST), the scene (e.g. a dialogue where NT is the same as ST), the summary (where NT is shorter than ST; the correspondence between the two in this category can vary greatly) and, finally, the ellipsis (where NT is infinitely shorter than ST). We do not get pauses in *Cirkus*. Even as a panel is a frozen moment time in comics is spatial. Some time will have gone as readers move from one panel to the next. In figure 1, it is even made explicit that one month goes by between some of the panels. What is interesting, is the fact that even though the story time ellipsis, which inhabits the blank space between two panels, is of one month, the avatar does not really change (he sinks a little and the colours darken). This sequence is strange, indeed. *Cirkus* is autobiographical (i.e. technically speaking it should be read as nonfiction) at a global or generic level. However, Nøhr reverts to fictive discourse on numerous occasions at a local level (cf. Nielsen, Phelan, & Walsh, 2015, p. 62 for a theoretical distinction between local and global fictionality). In the passage just mentioned, the secretary asked him to take a seat in the waiting room: Clearly, we are not invited to imagine that he literally spends +4 months sitting in a chair in a waiting room, even though this is what the visual side indicates. Nøhr also fictionalizes time categories, when the plot repeats itself in figures 2 and 3. The NT shortens in its depiction of the very same ST. This increases the number of panels and accelerates time-frequency. The panels become smaller and smaller just as they grow in numbers, which helps accelerate the speed of the repeated events. *Cirkus*, thus, represents a kind of spiralling downwards, a catabasis down to the hell that is the health care system, if you will. This is another blatant example of Nøhr's foray into fictive discourse at a local level: it is hyperbolic to suggest that he had to procure the statements from the doctor and the psychiatrist an infinite number of times. Nøhr exaggerates the singulative frequency to say something about the absurdity of the situation and to demonstrate the effect the circular, repetitive process has on him.

Conclusion

Counter-discourses directed at a society's psychiatric system – as one encounters in, e.g., literature with anti-psychiatry sentiments – has traditionally been centred on coercion in psychiatry (e.g., forced biomedical treatment, electro-convulsive therapy or compulsory admission to a mental institution). Nøhr, however criticizes the Danish welfare system's way of distributing help. In district psychiatry, treatment takes place on an outpatient basis, and help is distributed with reference to a generalized system of classification and diagnoses with set symptoms clusters. In order to receive help – in Nøhr's case, he needs to be exempted from job market availability – you first need to receive a diagnosis to prove that you are ill and, hence, in need of help. The quest to get help, thus, becomes a quest to receive a formal diagnosis that will elicit the help. It results in a system that is deemed highly bureaucratic and inefficient by Nøhr. The criticism is inherent in the very title, *Cirkus*. Of course, it refers to the repetitive circularity, but it also suggests that the patient is made to feel like a circus animal that is trained to perform tricks for treats. Nøhr, of course, presents the evidence of the plaintiff, so to speak. The Department of Health might make the counter-argument that placing people on disability pension is detrimental to the nation's financial situation and should, therefore, not be distributed lightly.

Revisiting Arthur Frank's notion of a chaos narrative, I have suggested that it is fruitful to supplement the chaos narrative by the concept of tellability. Furthermore, I have claimed, that Frank's argument; that the chaos narrative is really an anti-narrative, entails an implicit definition of narrative that is too reliant on plot. Put differently, the chaos narrative does not have to be defined as an anti-narrative, if plot is not viewed as indispensable to a definition of what constitutes a narrative. Experientiality or what it's are apt terms to account for narrativity in the chaos narrative. If a prototypical approach to definitions of narrative is employed, the chaos narrative *is* a narrative, just not a prototypical narrative. Experientiality or what it's like are foregrounded at the expense of plot.

In *The Wounded Storyteller*, Frank presents the chaos narrative as one that is predominantly communicated verbally, one that cannot be represented. I have suggested, that we modify this position by introducing what might be termed the mediated chaos narrative, in which the chaos is mimicked even as the representation is highly artificial and meticulously orchestrated. In the mediated chaos narrative, the ill protagonists are not just lost in the chaos. They can also exhibit irony and satire. To scrutinize the mediated chaos narrative in the interpretation of Nøhr, I supplemented the theory of the chaos narrative and of experientiality and what it's like with narratological distinctions between story and discourse, the narrating I and the experiencing I, and the time categories order, duration and frequency. Once the plot recedes into the background, the play with narrative and fictive discourse is foregrounded.

Finally, I have argued that the affordances of the graphic memoir makes it well suited to represent the mediated chaos narrative. The feedback loop between the theory and the empirical material led to critical arguments with theoretical implications. Even as I rely on small sample size – *Cirkus*, a single graphic memoir – I argue, that Nøhr employs the graphic memoir's affordances to experiment with narrative building blocks like narrative situations and time categories. Hence, the feedback loop between Nøhr's experimental graphic memoir and the theory applied in my interpretation thereof was crucial to the theoretical implications that it led to. Additional graphic memoirs – one example might be Art Spiegelman's *In the Shadow of No Towers* – might corroborate the findings, but it should also be emphasized that there are graphic memoirs about illness that qualify as restitution and quest narratives.

Notes

1 I would like to thank Felix Kühn Paulsen for introducing me to Nøhr's work and for inviting me to speak at a seminar at Aarhus University, where the ideas for this article were first presented.

2 *Circus* is in Danish. All translated quotations from Danish to English in this article are ad hoc translations by Lasse R. Gammelgaard.

References

Andreasen, S. (2017). Han tegner følelsen af stress og depression. *Seneste Nyt Kalundborg.* URL: https://sn.dk/Kalundborg/Han-tegner-foelelsen-af-stress-og-depression/artikel/643818?fbclid=IwAR0jefoKsyBJNDHXLhhhcR0eBsDmGL2-9aW85pgEdkl_TlyTeCVstuM9w2E. Viewed October 26 2018.

Aristotle (1981). *Poetics*. Tallahassee: Florida State University Press.

Baroni, R. (2011). Tellability. In P. Hühn et al. (Eds.), *The Living Handbook of Narratology*. Hamburg: Hamburg University. URL: http://www.lhn.uni-hamburg.de/article/tellability. Viewed October 26 2018.

Cohn, D. (1983). *Transparent Minds: Narrative Modes for Presenting Consiciousness in Fiction*. Princeton: Princeton University Press.

Fludernik, M. (1996). *Towards a 'Natural' Narratology*. New York, USA: Routledge. https://doi.org/10.4324/9780203432501

Frank, A. (1995). *The Wounded Storyteller: Body, Illness, and Ethics*. Chicago, USA: The University of Chicago Press. https://doi.org/10.7208/chicago/9780226260037.001.0001

Gardner, J. (20018). Autography's Biography, 1972-2008. *Biography, 31.1*, 1-26. https://doi.org/10.1353/bio.0.0003

Genette, G. (1980 [1972]). *Narrative Discourse: An Essay in Method*. (J. E. Lewing, Trans.). New York, USA: Cornell University Press.

Herman, D. (2009). *Basic Elements of Narrative*. Malden, USA: Wiley-Blackwell. https://doi.org/10.1002/9781444305920

Larsen, K. B. (15-04-2015). »Som en pludselig kvalme der ikke lader sig holde tilbage«. *Nummer 9: Magasinet om tegneserier*. URL: http://nummer9.dk/artikler/som-en-pludselig-kvalme-der-ikke-lader-sig-holde-tilbage/. Viewed October 26 2018.

Nielsen, H. S., J. Phelan, & R. Walsh (2015). Ten Theses about Fictionality. *Narrative, 23.1:* 61-73. https://doi.org/10.1353/nar.2015.0005

Nøhr, T. H. (2017). *Når jeg tegner…* Aarhus: Forlaget desAHJn.

Pedri, N. (2013). Graphic Memoir: Neither Fact Nor Fiction. In D. Stein & J.-N. Thon (eds.), *From Comic Strips to Graphic Novels: Contributions to the Theory and History of Graphic Narrative* (pp. 126-153). Boston: De Gruyter.

Rimmon-Kenan, S. (2006). What Can Narrative Theory Learn from Illness Narratives? *Literature and Medicine, 25.2*, 241-254. https://doi.org/10.1353/lm.2007.0019

Ryan, M.-L. (2005). Tellability. In D. Herman, M. Jahn, & M.-L. Ryan (Eds.), Routledge *Encyclopedia of Narrative Theory* (pp. 589-591). New York: Routledge.

Originalartikel

A typical patient with depression?

A comparative linguistic analysis of accounts by general practitioners and psychiatrists

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In Denmark and internationally there is a push for enhanced collaboration between general practice and the psychiatric sector in the treatment of patients with depression. Linguistic and other qualitative studies into doctor-patient interaction have shown that general practitioners (GPs) and psychiatrists have different understandings of depression, which could hamper collaboration. The present study adds to linguistic research of the understanding of depression in the two sectors by examining healthcare communication in a context of representation: how doctors talk about their patients in interviews, rather than how they communicate with their patients in consultations. We demonstrate that the two groups of doctors have diverging representations of patients with depression. Most GPs present patients as individuals whose condition is explained by psychosocial circumstances; whereas psychiatrists predominantly present patients as categories. This difference is evidenced by *how the two groups respond to the interviewer's elicitation of patient stories. The GPs employ personal or specific narrative genres, whereas the psychiatrists use general narrative genres, indicating that the two groups occupy their own separate spaces within what is termed the narrative field. We also demonstrate that these different representations concur with variations in interactional patterns in the interview context, enhancing the gap between the professional identities of the two groups of doctors and, consequently, their conceptualizations of depression. The difference between the groups could be suggestive of cultural differences between the two sectors, caused by their different roles and working conditions in the health care system, which could pose a challenge to future cooperation.*

Introduction

In Denmark, as in other countries, there has been an expressed wish to establish shared care between general practice and psychiatry for the increasing number of patients with depression (Gask 2005, Eplov, Lundsteen & Birket-Smith 2009, Eplov et al. 2014). In the US and the UK in particular, different collaborative care models have been introduced and tested with moderate results and with outcomes dependent on the health care system in each country (Archer et al. 2012, Richards et al. 2016, Coventry et al. 2012). In Denmark, a collaborative care model is currently being tested (Brinck-Claussen et. al 2017). There is a growing awareness, however, that effective collaboration is dependent upon shared understanding among professionals (May 2013).

Studies using interactional linguistic or other qualitative methods have shown different understandings of depression in general practice and in psychiatry (e.g. Davidsen & Fosgerau 2014a, Davidsen & Fosgerau 2014b, Fosgerau & Davidsen 2014). To further explore the understandings of depression among general practitioners (GPs) and psychiatrists (PSs) in Denmark, this article will apply a representational linguistic method by looking at how the doctors construct patient identities in an interview setting. More specifically, our aim is to examine how GPs and PSs conceptualize a typical patient with depression. In addition, interactional phenomena between interviewer and interviewees are taken into consideration to provide a full picture of the two groups' views of their patients.

Linguistic investigations of medical discourse have dealt with doctor-patient interaction (for a review see Nielsen 2010). They are typically within the framework of Conversation Analysis, focusing on interactional settings (e.g. Sacks et al. 1974, Heritage & Maynard 2006, Davidsen & Fosgerau 2014a, Fosgerau & Davidsen 2014);

or they have used Critical Discourse Analysis, focusing on how e.g. pre-defined power structures are expressed in the interaction (Fairclough 1989, Wodak 1997). In contrast, how doctors talk *about* patients is treated by other sciences (e.g. Chew-Graham, Davidsen 2008, Davidsen & Fosgerau 2014b) that have also included the narrative perspective (Davidsen & Reventlow 2011).

The narrative perspective has gained increasing influence within different forms of science since about 1980, e.g. philosophy, psychology and law (Ricoeur 1980, Schafer 1980), leading to what is called *the narrative turn* (Sarbin 1986, Jensen & Mattingly 2009) with incorporation of narrative conceptualizations into a broad variety of fields (e.g. Bamberg 2010, Bruner 1986, 2002 and White 2007). Additionally, there is an increased emphasis in the medical literature on the value and importance of language in working with depressed patients (Dowrick 2009). Dowrick represents a constructionist view of language and sees narrative as a tool, which has the capacity to shape our own and others' selves (Dowrick 2009, p. 219). Building on this widely accepted concept, we argue that language and narrative are not only central to the interaction with patients as tools to encourage them to tell their stories, but language also plays a central role in reflecting and shaping the reality of the professionals treating the patients.

Choosing the interview as the object of investigation provides an opportunity for supplementary representational perspectives to the studies of doctor-patient interactions. We apply this perspective to the medical professionals in interviews talking *about* their patients.

Method

Data collection

The informants were 12 GPs and 11 PSs, selected purposively from two regions in Denmark to control for the range of demographic differences among the doctors, all of whom were covered by a collective agreement with the health authorities or employed at a public hospital. The gender distribution was equal in the two groups; the age range was comparable, for the PSs 45-62 years and for the GPs 43-66 years. The data consisted of semi-structured interviews (Kvale 1997) conducted by the second author who is a GP and who has also worked in psychiatry. Before conducting the actual interview, the interviewer informed the participants of this professional background. Thus, the interviewer's experience from both fields provided an opening for possible alignment with both groups of professionals. An interview guide was designed to ensure that all desired domains were covered and to consider foreseen difficulties. The guide was suggestive, not prescriptive. The questions were neutral, open and addressed the participants' understandings and conceptualizations of depression (Smith & Osborn 2003). The interviews were not conducted with the present study in mind. Rather, the present study was motivated by an observation that the interviews were generally non-narrative. We wished, therefore, to identify passages in the interviews that specifically encouraged narrative accounts. We elaborate on this approach below. The interviews were audio-recorded and transcribed according to the Clan conventions (Clan transcription conventions 2018).

Demarcation of the genres

Our object of interest was an elicitation question worded along the lines of 'Do you remember a typical patient with depression?' or 'Do you remember a patient story?' Although, this question was not included in the interview guide (see above), it occurred in most interviews[1]. The recurrence of this question makes the speech situation across the interviews comparable (cf. also Gregersen & Barner-Rasmussen 2011). The research interview is a genre in which the interviewer is trying to obtain information, and the interviewee is the provider of this information (Kvale 1997: 19). The current interviews were one-to-one interviews, meaning that there was no competition for the right to the floor and the interviewees were therefore relatively free to elaborate the answers as they wished (e.g. Møller 1993: 294-5). This uncompetitive setting often resulted in rather long, monologic stretches of speech, some of which were narrative in that they presented chronologically ordered past events (Eggins & Slade 1997, Gregersen & Barner-Rasmussen 2011). It is such narrative stretches prompted by the elicitation question that this study is concerned with: what did the two groups of doctors do when presented with an elicitation question within an uncompetitive frame?

Additional analyses

In addition to narrative genres, we examined interactional phenomena associated with the production of the doctors' narrative genres. These phenomena include the grammatical number in question-answer sequencings, as well as negotiations of the interviewer's elicitation question. To substantiate our argumentation, we also look at the thematic content of the narrative genres.

Theoretical framwork: The narrative genres

Departing from classic sociolinguistic narrative theory (Labov & Waletzsky 1967), which views narratives as projecting social and cultural identities, we argue that speakers' linguistic choices play a determining role in their conceptualizations of patients with depression. Therefore, a linguistically founded narrative framework can provide a fine-grained approach to narrative investigations of understandings of patients with depression. The study is based on an analysis of three different speech genres: *the personal narrative, the specific account and the general account*. These three types of narrative genre are based on findings from studies of language change at the LANCHART Centre at the University of Copenhagen, where a large corpus study of so-called sociolinguistic interviews has suggested that *the narrative field* is covered by these three genres (Gregersen & Barner-Rasmussen 2011:15). The three genres are replicated below.

The personal narrative and the specific account

The most well-established of the three genres is the *personal narrative* as defined by the sociolinguist William Labov (e.g. Labov & Waltezky 1967, Labov 1972). Through a study of New Yorkers' narratives about their experiences of life-threatening situations, Labov discovered a recurrent structure in the way the informants told stories (Labov &Waletzky 1967: 26). Labov views the overall narrative structure "*[…] as a series of answers to underlying questions […]*" (Labov 1972: 370) followed by a coda:

A. Abstract: what was this about?
B. Orientation: who, when, what, where?
C. Complicating Action: then what happened?
D. Evaluation: so what?
E. Result: what finally happened?
F. Coda

The last element, coda, closes the narrative by bridging the narrative world and the current speech situation (Labov 1972: 370). Of the six elements, Complicating Action and Evaluation are obligatory (Eggins & Slade 1997: 237). Further, for the story to qualify as a personal narrative it must be rendered as reportable and be centred on one unique event, implying a climax and a subsequent resolution, and the narrator must have been a participant in the narrated events (Labov 1972: 355, Labov 1997: 7-8).

The *specific account* is similar to the personal narrative in focusing on a specific event in the past. Regarding participation, the narrator must have been a participant in, or at least a witness to, the event. The mode differs from that of the personal narrative in treating the event in a descriptive rather than in a performed mode, just as the focus is on the process rather than on a central event. This mode is typically realized as listing events, using 'and then… and then… and then…', and the amount of detail is less than in a personal narrative (Eggins & Slade 1997: 259). The specific account may contain some of the same elements as those described in the personal narrative, but the only obligatory element is the chronological rendering of a sequence of events (Eggins & Slade 1997).

The general account

The general account is a rendering of recurrent past events, routines or habits, or general processes and sequences, and thus differs from the other two narrative genres in terms of specificity (Gregersen & Barner-Rasmussen 2011: 15-16). As in the specific account, this narrative mode is descriptive rather than performed. In contrast to the two other narrative genres, the general account need not be self-experienced (LANCHART, 2011: 44).

All three genres are narrative in structure and serve to present a progression. They do, however, differ in degrees of specificity and detail, reportability and evaluation (see also Table 1 below). In relation to these parameters, the personal narrative represents one end of the narrative field or spectrum, and the general account the other. Central to the present study is, however, that both the personal narrative and the specific account deal with the particular and, therefore, serve to project a specific patient. This specificity makes these two genres fundamentally different from the general account, which, as we will show, the doctors employ to talk about patients as a generic group. The assumption for the present study is that the doctors' selections from the narrative field indicate how they conceptualize patients with depression, and how they construct patient identities.

Summary of narrative speech genres

The characteristics of the three narrative genres are summarized in the table below:

Narrative genres	**Personal narrative**	**Specific account**	**General account**
Participation	Central role	Central role	No requirement
Narrative mode	Specific, performed	Specific, descriptive	General, descriptive
Reportability	Reportable	Non-reportable	Reportable or non-reportable
Obligatory elements	Complicating action and evaluation	Chronological rendering of events	None

Table 1: Characteristics of the three narrative genres

Results

Narrative Genres

A count of the different speech genres produced by the GPs and PSs showed the following results:

GENRE	Personal narrative	Specific account	General account
11 GPs[2]	4	4	3
9 PSs[3]	2	3	4

Table 2: Distribution of narrative genres in the GP and PS groups

The most notable difference between the two groups is the production of personal narratives (4 vs. 2). Even though the doctors were encouraged to tell a story about a typical patient, relatively few doctors produced a fully-fledged story. Regarding the number of accounts, the two groups showed similar tendencies: the GPs producing slightly more specific accounts (4 versus 3) and the PSs slightly more general accounts (4 versus 3). If we combine the genres that per se are specific, i.e. the personal narrative and the specific account, and compare these with the general genre, the general account, the tendency toward different preferences within the two groups is strengthened. In the GP group, 8 of 11 genres are specific, whereas this is only the case in 5 of 9 instances in the PS group. To illustrate, (1) is a personal narrative produced by a GP (GP6), where INT represents the interviewer and INF represents the interviewee or informant:

(1)

Element	Personal narrative
Elicitation	INT: do you remember any patients? INF: well I think # I have already # we have already # INT: you just said burning <INF: # yes #> on the tongue {is} it was {n-} is it a patient who # INF: yes! it is a it # <INT: # has had {these symptoms}> INT: {or} # yes <INF: # yes: it ehm> # INF: well she! is not that good an example it {it} is just because ehm # it was more because #{yes she} I just mentioned Lyr- # la- la- Lyrica and ehm # <INT: # mm> # there were some who had suggested INT: yes # INF: suggested it # INT: yes #
Abstract	INF: but but I think # no what can we I don't know if I can think of any examples but sometimes there are <INT: # no #> some patients where I think # yes it may well! be that it is what is called somatisation but I think that is also very much down the # <XAD: # yes> # depressive anxie- # <XAD: # yes> alley right # INT: yes

Orientation	INF: ehm that ehm # oh I have I have a young Tunisian: ehm man ma- a man of Tun: ehm Tunisian origin
Complicating Action	who # first said that he had a # fever # fever he said and then he did like that and then <INT: # yes # yes> # I completely misunderstood and then I showed him a thermometer and then he was completely terrified # about it # about about <INT: # yes # yes #> the way we measure! ha <INT: # mm> the temperature <INT: yes ha> #
Result	but it turned {out} that he had a pricking sensation # INT: yes #
Evaluation	INF: and # of course there is something: # ethnical and cultural to that! # but # he is co:mpletely # out of his wits because of th- <INT: # mm> because of- of- of- this thing # INT: yes # INF: a- a- and th- # I am thinking it i:t # these are symptoms where you: # must be aware if # if there are men- # me:ntal conditions and if it could be <INT: # yes #> anxiety <INT: # yes #> # INT: yes
Coda	INF: anxiety depression are ehm as such <INT: # yes yes #> # in the medical field I think they have been mixed # <INT: # yes> # maybe a bit too much together

(GP6)

In this personal narrative, the GP talks about a patient whose cultural background led to a misunderstanding in the consultation. The GP suspected that the patient's somatic symptoms could be related to a mental condition. By means of this personal narrative, the GP tries to show how somatic symptoms, in this case, combined with a different cultural and ethnical schism, may be rooted in an underlying mental condition and touches upon the importance of differentiating between various mental conditions, such as anxiety and depression.

The second excerpt (2) is a general account produced by a PS (PS6):

(2)

General account
INT: so # how # if you are to paint! a # typical depression- # {-picture-} or perhaps you can remember a # certain patient! you perhaps can #
INF: well we have a completely <INT: # mention #> fixed proce:- so to speak they are called into a pre-interview # <XAD: # mm> now we have just changed it so that they actually must come to two! pre-interviews #
INT: right #
INF: but often most of it we are able # to clarify in the first pre-interview <INT: # yes #> where I <INT: # yes #> participate and then there's also a district nurse # <INT: # yes> # and then we make a completely! standard anamnesis recording it takes # just under an hour #
INT: mm
INF: # mm mostly # and go through just like when you make any # other medical record # {with dispositions and} allergies and <INT: # yes> previous: # go through all these other organ systems systematically how do you say it to: mm # partly to find out if: # they have! some kind of illness they have forgotten to tell about: # there can be side effects # or to # also typically to be able to describe! if there is # for example if they mention that they have a headache regularly so if they come back a:nd # complain about headache in connection with start-up of medication! then we can kind of look back and say well they # actually also had this before is it <INT: # mm #> congestion! or <INT: # mm #>
INT: # yes #
INF: whatever it may be #

(PS6)

In (2) the PS describes the diagnostic process related to depression. The focus is on bodily/somatic symptoms and medical treatment rather than on a certain patient's life story, which could provide an explanation for the patient's depression, as was the case in the GP narrative in (1).

The thematic focus along with the general mode provides interesting information about the PS's focus and, accordingly, the PS's mindset in relation to depression. It conveys a much stronger medical and diagnostic focus than the GP's narrative in (1). We will return to differences in thematic foci later. Further, the PS's choice of genre is interesting in relation to the interviewer's question, which ends with an encouragement to highlight a specific patient: "*perhaps you remember a certain patient you can tell about*". However, the psychiatrist seems to overrule this encouragement by maintaining a general focus. This phenomenon will be treated in detail later. These results suggest that the GPs choose to highlight individual patients whereas the PSs conceptualize patients in more general terms, leaving out references to individual patients' stories.

Thematic focus in the speech genres

The thematic focus in the speech genres also reveals a difference between the two groups. In all of the GP elicitations, the patient's psychosocial background forms part of the storyline. The GPs tend to highlight the explanations for depression by referring to family relations, life-changing events or – as is the case in (1) – cultural and ethnic aspects. This focus is only found in 5 of 9 PS elicitations. In 3 of these 5 instances, a general account is chosen as the narrative mode, indicating that when the PSs choose to thematize patient backgrounds, the tendency is to paint a general picture of circumstances, instead of highlighting specific patients. In this way, the predominant picture established by the PS group is one of generality, which again supports the argument that this group of doctors conceptualize the psychosocial aspect of depression as a dimension that can be categorized, which is less the case with the GPs.

Singular/plural phrasing of elicitation questions in relation to narrative genres

The doctors' genres as a response to the elicitation question support their different takes on constructing depression as illustrated by the following:
(3); if you were to mention a typical patient with depression who do you think of? (question to PS1)

(4); do you remember any stories as examples of some of those different types? (question to GP9)

In (3), the interviewer's question is posed using the singular, whereas in (4) the interviewer employs the plural form. The hypothesis behind the singular-plural distinction is that a question posed in the singular would evoke a story about a single patient realized as a specific genre, either a personal narrative or a specific account; and conversely, a question in the plural would result in a general account.[4] The table below displays the correlations between the phrasing of the elicitation question and the production of genres in the two groups:

	GP group	PS group
Total production of genres	11	9
Singular elicitation>specific genre	6	4
Singular elicitation>general genre	3	3
Plural elicitation>specific genre	2	1
Plural elicitation>general genre	0	1

Table 3: Singular/plural distinction in questions and answers in the GP and PS groups

A comparison of the production of genres between the two groups in relation to the singular/plural distinction points to two conclusions. First, in the GP speaker group, both questions phrased in the plural prompt a specific genre (i.e. personal narrative or specific account). Even though a question in the plural would be expected to elicit a general genre, the GPs choose to go beyond this match and adapt the question to their own use, narrating a story about a single patient through a specific genre. This count supports the tendency that the GPs view their patients as individuals, and that the emphasis on single fates takes precedence over diagnostic processes and placing the patient in a certain category of illness. Second, in 3 of 9 PS interviews, responses to singular elicitation are with a general genre. Also, the PSs respond to the elicitation question in the plural with a plural genre, which contrasts with how the GP group handles questions in the plural. The GPs do produce general genres on the basis of elicitation questions in the singular (3 of

11), however, this tendency seems overruled by the fact that they predominantly seek the specific genre no matter the phrasing of the question.

Taking on the task?

In many of the interviews, the speakers produce a genre immediately after the interviewer's elicitation question. In some interviews, however, the doctors negotiate the elicitation question before producing a genre. The negotiation may be any inserted talk between the elicitation question and the start of the narrative genre, such as clarifying questions from the interviewees as seen in (5), which is an instance of negotiation (PS5):

(5)
1 INT: Do you remember like a # typical # patient with the: unipolar depression #
2 INF: yes I have just had one ehm here oh with a unipolar! are you asking for now here <INT: 3 # yes ehm> # right # <INT: # yes>
4 INT: it can also be the other type
5 INF: oh it was {just because} the other <INT: # ehm yes #> I was thinking about the other
6 <INT: # yes yes yes>
7 INT: but you #
8 INF: ehm # <INT: # can also tell about that > # ehm well what now what what now then
9 {then} now I have just lost the thread because now now now s- you asked xxx <INT: no yes I 10 was asking if>
11 INT: you could remember a # like a # patient you thought was typical with regard and there I 12 was actually thinking about the un- unipolar but I would <INF: #unipolar yes #> also like to 13 hear about the other one #
14 INF: yes
15 INT: yes #
16 INF: : ehm but it is more I actually think the unipolar is the most interesting to you because 17 <INT: # yes yes> because it is the one that i:s most # it is that type tha:t comes into general 18 practice <INT: # yes #> typically right <INT: # yes #> # ehm yes # we:ll I remember a lot so 19 what is it that you would like to know then I can # <INT: # yes but I would like to know>
20 INT: kind of ehm it it ehm and of course that is probably not the typical kind but ha well

21 when I am asking for a typical patient then it is <INF: # yes #> a kind of a picture that # that 22 mirrors #
23 INF: yes # <INT: what>
24 INT: you would # think it is # it is what you often see right # yes <INF: # okay #> #
(PS5)

A count of the negotiations that take place after the elicitation question in the interviews shows a difference between the two groups. Whereas 7 of 11 GPs produce a genre immediately after the elicitation question, this is only the case in 4 of the 9 possible PS responses. Excerpt (5) is taken from a PS interview and conveys an extended negotiation, where nine turns are inserted before the genre is produced. This negotiation could be regarded as a wish to provide precise information, fulfilling the purpose of the speech event (the interview), and ultimately the research project, by ensuring the interviewer's takeaway from the interview. This is also supported by the PS's counter-question: "*What is it that you would like to know?*" (l. 19), along with the extensive use of meta-language throughout the sequence, which underlines the PS's focus on identifying the task given by the interviewer. Further, the story is realized as a general account, which supports our assertion that the PSs tend to conceptualize patients in categorical terms rather than in specific encounters. The predominance of negotiation in the PS group could be seen as an affirmation of the professional identity they possess as experts, as opposed to the GPs. In (5), the PS even decides what the most valuable information for the interviewer would be (ll. 16-18).

Discussion: Is shared care possible?

Different linguistic patterns as an indication of different conceptualizations of depression

The starting point for this study was the need for new evidence about the understanding of depression in the primary and secondary health sectors with the perspective of creating possibilities for shared care between general practice and psychiatry. Different reviews have shown that shared care is associated with significant improvement in depression compared with usual care (Smith et al 2017; Sighinolfi et al 2014; Archer et al 2012). Nevertheless, there seem to be covert barriers between the two groups of professionals (Gask 2005), which could hamper enhanced collaboration (Overbeck, Kousgaard & Davidsen, 2018b). The analyses of the two groups' representations of patients in combination with interactional phenomena in the interviews have suggested differences in the ways the GPs and the PSs conceptualize patient identities, along with their own professional identities. The divide between specific and general representations was particularly prevalent in the interviews. The result that the GPs tend to conceptualize specific patients indicates that the GPs take a more individual approach to patients. Dimensions such as specific life-circumstances, critical events and causes etc. are central in establishing a helpful and full-bodied picture of the patient. An explanation for these different preferences in the two groups may be found in the circumstances under which they meet their patients. GPs often have a longstanding relationship with patients, which could explain why they render specific patients to a greater degree than the PSs, whose training focuses on achieving competence in diagnoses and medication (Stange 2009). The results also mirror the circumstance that patients in GP consultations are un-referred, often with undifferentiated symptoms, implying a patient-centred approach where the patient sets the agenda (Langberg, Dyhr & Davidsen 2019). In contrast, the purpose of psychiatric consultations is to decide whether or not a given condition is present, implying that the PSs' focus is on the diagnosis rather than on the patients themselves.

A central issue is: to what degree this mindset of the GPs and their approach to patients can be integrated into shared care between sectors (Overbeck, Kousgaard & Davidsen 2018a). The GPs must refer to diagnostic criteria formulated in psychiatry (Gask, Klinkman, Fortes & Dowrick 2008), but they do not always consider these criteria relevant in general practice (e.g. Davidsen & Fogtmann 2014b). In the Danish Collaborative Care study, the GPs thought that the diagnostic criteria for being included in the project were too rigid and did not mirror the clinical reality in general practice (Overbeck, Kousgaard & Davidsen 2018a). In the study, psychiatric nurses, employed in secondary care psychiatry, treated patients in general practice (Brink-Claussen et al. 2017). Dialogue between the sectors was mostly monological with the psychiatric nurses giving reports. On the rare occasions that dialogical communication took place, with mutual contributions from GPs and care managers, there was a development of a shared understanding (Overbeck, Kousgaard & Davidsen 2018b). Another study of the GP and PS interviews demonstrated significant differences in the two groups' grammatical uses of depression terminology (Pedersen 2018). These differences can also be seen as manifestations of diverging understandings of depression and seem to confirm a lack of integration of understandings between psychiatry and general practice. This could possibly hamper collaboration about patients and increase rejection of GPs' referrals to psychiatry (May 2013).

The interview as an interactional discipline

The present study also showed differences in interactional patterns in the two groups of doctors. These differences were manifested in varying approaches to the interviewer and the interview situation, just as subtle variations in the interviewer's interview technique may have contributed to slightly different results within the two groups. These interactional observations add to the notion that the two groups have diverging professional identities. The different interactional structures can be illuminated further by looking at the context i.e. the research interview. Kvale argues that:

> *"The research interview is an inter-view where knowledge is constructed in the interaction between two people. The interviewer and the subject act in relation to each other and reciprocally influence each other. The knowledge produced in a research interview is constituted by the interaction itself, in the specific situation created between an interviewer and an interviewee. With another interviewer, a different interaction may be created and a different knowledge produced."* (Kvale 2007: 11-13)

The differences between the two groups, not only in terms of representation but also in how the representations are fueled in the interaction, could be supported by Kvale's observation. The relation between the interviewer, who has a long history as a GP, and the doctors could be a local, contextually motivated realization of broader professional, and not least cultural, takes on depression and patients with depression.

Two studies of the same 23 doctors' interactions with their patients based on video-recordings of consultations have shown that GPs and PSs have different approaches to interacting with their patients (Davidsen & Fosgerau 2014a, Fosgerau & Davidsen 2014). One of the studies looked at how the doctors had different ways of handling patients' emotional disclosures, and concluded that:

> *"The differences between GPs and psychiatrists might mirror deeper differences in the conceptualization of depression as a biomedical disease or a condition caused by life circumstances [...] A lack of consensus might affect fruitful interdisciplinary work."* (Davidsen & Fogtmann 2014a: 66).

The evidence from the current and previous studies that the two groups display different grammatical, narrative and interactional patterns could indicate that practical and structural factors in the healthcare sectors do not provide a full explanation for these findings. Instead, the difference between the two groups could be suggestive of more fundamental cultural differences between the two sectors, partly caused by their different roles and working conditions in the health care system (Stange 2009, Stange & Ferrer 2009, McWhinney 1996), which could pose a challenge to future cooperation.

Conclusion

In this study, we have demonstrated that the GPs present a more substantial and personal picture of their patients with depression than do the PSs. These representations of patients, as well as interactional patterns, could be indicative of GP and PS approaches to depression as an illness, to patients and treatment and, ultimately, to the foundation for shared care. By providing precise structural descriptions of health care interview discourse, our linguistic approach may be considered a methodological alternative to more qualitative, thematically based methods within the field of social medicine, just as we expect that linguistic analyses of health care interviews may prove fruitful in future collaboration across academic disciplines.

Notes

1 The interview guide was suggestive rather than prescriptive, consisting of conversational topics rather than specific questions with a certain wording. Hence, in two of the interviews, the interviewer did not pose the question about a typical patient with depression.

2 Of the 12 GPs, 11 produced a genre when asked the elicitation question, whereas one attempt was unsuccessful.

3 Of the 11 PSs, two were not presented with the elicitation question, which makes a total of 9 PS speech genres.

4 In cases of ambiguity as regards the singular/plural distinction, it is the last part of the question – i.e. how the interviewer ends up phrasing the question – that has been included in the count.

Litterature

Archer, J., Bower, P., Gilbody, S., Lovell, K., Richards, D., Gask, L., Dickens, C., & Coventry, P. (2012). Collaborative care for depression and anxiety problems. *Cochrane Database of Systematic Reviews*, 10. doi:10.1002/14651858.CD006525.pub2.

Bamberg, M. (2010). Who am I? Narration and its contribution to self and identity. *Theory & Psychology*, 21(1), 1-22. https://doi.org/10.1177/0959354309355852

Brinck-Claussen, U. O., Curth, N. K., Davidsen, A. S., Mikkelsen, J. H., Lau, M. E., Lundsteen, M., Csillag, C., Christensen, K. S., Hjorthøj, C., Nordentoft, M., & Eplov, L. F. (2017). Collaborative care for depression in general practice: Study protocol for a randomised controlled trial. *Trials*, *18(1)*, 344. doi: 10.1186/s13063-017-2064-7

Bruner, J. (2002). *Making Stories. Law, Literature, Life*. Cambridge, MA: Harvard University Press.

Bruner, J. (1986). *Actual Minds, Possible Worlds*. Cambridge, MA: Harvard University Press.

Clan transcription conventions: *https://dgcss.hum.ku.dk/aarsberetninger/rapporter/clan-oversigt.pdf/Clan-oversigt1.pdf.*). Retrieved October 24, 2018.

Chew-Graham, C.A., May, C.R., & Headley, S. (2000). The burden of depression in primary care: A qualitative investigation of general practitioners' constructs of depressed people in the inner city. *International Journal of Psychiatry in Clinical Practice, 6(4*), 137-141. doi:10.1185/135525700543352

Coventry, P. A., Lovell, K., Dickens, C., Bower, P., Chew-Graham, C., Cherrington, A., Garrett, C., Gibbons, C. J., Baguley, C., Roughley, K., Adeyemi, I., Keyworth, C., Waheed, W., Hann, M., Davies, L., Jeeva, F., Roberts, C., Knowles, S., & Gask, L. (2012). Collaborative Interventions for Circulation and Depression (COINCIDE): Study protocol for a cluster randomized controlled trial of collaborative care for depression in people with diabetes and/or coronary heart disease. *Trials, 13:139*. doi: 10.1186/1745-6215-13-139

Davidsen, A. S. (2008). *Mentalization, Narrative and Time - A qualitative study about psychological interventions in general practice (PhD thesis).* Copenhagen: The Research Unit of General Practice.

Davidsen, A.S., & Reventlow, S. (2011). Different approaches to understanding patients in general practice in Denmark: A qualitative study, *British Journal of Guiding and Counselling, 39(3),* 209-226. https://doi.org/10.1080/03069885.2011.552600

Davidsen, A. S., & Fosgerau, C. F. (2014a). General practitioners' and psychiatrists' responses to emotional disclosures in patients with depression. *Patient Education and Counseling, 95(1),* 61-68. doi: 10.1016/j.pec.2013.12.018

Davidsen, A. S., & Fosgerau, C. F. (2014b). What is depression? Psychiatrists' and GPs' experiences of diagnosis and the diagnostic process. *International Journal of Qualitative Studies on Health and Well-Being, 9(1),* [24866]. doi: 10.3402/qhw.v9.24866

Dowrick, C. (2009). *Beyond depression - a new approach to understanding and management*. New York: Oxford University Press. https://doi.org/10.1093/med/9780199545292.001.1

Eggins, S., & Slade, D. (1997). *Analysing Casual Conversation*. London: Cassell.

Eplov, L.F., Lundsteen, M., & Birket-Smith, M. (2009). *Shared care for ikke-psykotiske sygdomme. Anbefalinger på baggrund af en systematisk litteraturundersøgelse*. Copenhagen: Danske Regioner.

Eplov, L. F., Davidsen, A. S., Christensen, K. S., Mikkelsen, J. H., Lau, M., Nielsen, J. N., et al. (2014). P*roject Collabri. The effect of a Danish model of collaborative care for people with anxiety and depression in general practice*. Retrieved September 25, 2014, from http://www.psykiatri-regionh.dk/menu/Forskning+og+udvikling1/Udvikling/Projekt+Collabri/

Fosgerau, C. F., & Davidsen, A. S. (2014). Patients' perspectives on antidepressant treatment in consultations with physicians. *Qualitative Health Research, 24*, 641-653. doi: 10.1177/1049732314528813

Gask, L. (2005). Overt and covert barriers to the integration of primary and specialist mental health care. *Social Science & Medicine 61(8)*, 1785-94. doi:10.1016/j.socscimed.2005.03.038

Gask, L., Klinkman, M., Fortes, S., & Dowrick, C. (2008). Capturing complexity: The case for a new classification system for mental disorders in primary care. *European Psychiatry, 23(7)*, 469-476. doi:10.1016/j.eurpsy.2008.06.006

Gregersen, F., & Barner-Rasmussen, M. (2011). The logic of comparability: On genres and phonetic variation in a project on language change in real time. *Corpus Linguistics and Linguistic Theory, 7(1)*, 7-36. doi:10.1515/CLLT.2011.002

Jensen, U. J., & Mattingly, C. (2009). *Narrative, self and social practice*. Aarhus: Philosophia Press.

Kvale, S. (1997). *InterView*. Copenhagen: Hans Reitzels Forlag.

Kvale, S. (2007). *Doing interviews*. Thousand Oaks: Sage Publications. https://doi.org/10.4135/9781849208963

Labov, W., & Waletzky, J. (1967). Narrative analysis: Oral versions of personal experience. *Journal of Narrative and Life History, 7*, 1-38. https://doi.org/10.1075/jnlh.7.02nar

Labov, W. (1972). *Sociolinguistic patterns*. Philadelphia: University of Pennsylvania Press.

LANCHART (2011). *Coding manual for Discourse Context Analysis*: http://dgcss.hum.ku.dk/aarsberetninger/rapporter/IIVkodningsmanual__opdateret_januar_2011___2_.pdf/ Retrieved October 24, 2018.

Langberg, E., Dyhr, L. Davidsen, A. (2019). Development of the concept of patient-centredness - A systematic review. *Patient Education and Counseling*. doi:10.1016/j.pec.2019.02.023

May, C. (2013). Towards a general theory of implementation. *Implementation Science, 8(18*). doi:10.1186/1748-5908-8-18

McWhinney, I. R. (1996). The importance of being different. *British Journal of General Practice, 46(408)*, 433-436.

Nielsen, S. B. (2010). Konversationsanalyse af læge-patient-samtaler: status, overblik og muligheder. *NyS. Nydanske Sprogstudier, 38(38)*, 10-37. https://doi.org/10.7146/nys.v38i38.13517

Overbeck, G., Davidsen, A. S., & Kousgaard, M. B. (2016). Enablers and barriers to implementing collaborative care for anxiety and depression: a systematic qualitative review. *Implementation science, 11(1)*, 165. doi:10.1186/s13012-016-0519-y

Overbeck, G., Kousgaard, M. B., & Davidsen, A. S. (2018a). The work and challenges of care managers in the implementation of collaborative care: A qualitative study. *Journal of Psychiatric and Mental Health Nursing, 25(3)*, 167-175. doi:10.1111/jpm.12449

Overbeck, G., Kousgaard, M. B., & Davidsen, A. S. (2018b). Enactments and experiences of 'enhanced interprofessional communication' in collaborative care - a qualitative study. *Journal of Interprofessional Care*, doi:10.1080/13561820.2018.153810

Pedersen, H. S. (2018). Grammatisk talesprogsanalyse som tilgang til at studere forståelser af depression. Gengivet sprogbrug som eksempel. *NyS, Nydanske Sprogstudier, (1)54*, 156-182.

Richards, D. A., Bower, P., Chew-Graham, C., Gask, L., Lovell, K., Cape, J., Pilling, S., Araya, R., Kessler, D., Barkham, M., Bland, J. M., Gilbody, S., Green, C., Lewis, G., Manning, C., Kontopantelis, E., Hill, J. J., Hughes-Morley, A., & Russell, A. (2016). Clinical effectiveness and cost-effectiveness of collaborative care for depression in UK primary care (CADET): A cluster randomised controlled trial. *Health Technology Assessment, 20(14)*, 1-192. doi:10.3310/hta20140

Ricoeur, P. (1980). Narrative time. *Critical Inquiry, 7(1)*, 169-190. https://doi.org/10.1086/448093

Sarbin, T. R. (1986). *Narrative psychology, the storied nature of human conduct*. New York: Praeger.

Schafer, R. (1980). Narration in the psychoanalytic dialogue. *Critical Inquiry, 7(1)*, 29-53. https://doi.org/10.1086/448087

Sighinolfi, C., Nespeca, C., Menchetti, M., Levantesi, P., Belvederi Murri, M., & Berardi, D. (2014). Collaborative care for depression in European countries: A systematic review and meta-analysis. *Journal of Psychosomatic Research, 77(4)*, 247-263. doi:10.1016/j.jpsychores.2014.08.006

Smith, J. A., & Osborn, M. (2003). Interpretative phenomenological analysis. In J. A. Smith (Ed.), *Qualitative psychology, 51-80*. London: Sage.

Smith, S.M, Cousins, G., Clyne, B., Allwright, S., & O'Dowd, T. (2017). Shared care across the interface between primary and specialty care in management of long term conditions. *Cochrane Database of Systematic Reviews, 2*. doi:10.1002/14651858.CD004910.pub

Stange, K. C. (2009). The generalist approach. *Annals of Family Medicine, 7(3)*, 198-203. doi:10.1370/afm.2145 https://doi.org/10.1370/afm.2145

Stange, K. C., & Ferrer, R. L. (2009). The paradox of primary care. *Annals of Family Medicine, 7(4)*, 293-299. doi:10.1370/afm.1023 https://doi.org/10.1370/afm.1023

White, M.K. (2007). *Maps of narrative practice*, New York and London: W. W. Norton & Company.

Originalartikel

Bridging Disciplines

On Teaching Empathy Through Fiction

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In 2016, the Norwegian government announced that public health and life mastery would be an overarching topic in all the subjects in high schools. Empathy may predict mental health issues, and fiction can encourage empathy. This article illustrates narrative empathy through the Norwegian novel Begynnelser (Beginnings) (2017) by Carl Frode Tiller. The aim is, to give a theoretical account of combined methods and insights from literary studies and narrative medicine in order to investigate how narrative empathy can emphasize mental health and life mastery in Norwegian literature when taught in high school. The article draws upon the thoughts of Bloom, Nussbaum, van Lissa et al. and Bryant on empathy and its meaning, Suzanne Keen's theory of narrative empathy and pedagogical perspectives from the field of narrative medicine, represented by Rita Charon. Begynnelser connects to the concept of life mastery and through a close reading of the novel in a sociocultural context, students can learn to recognize important details in the text. Character identification and narrative situation are two main techniques in narrative empathy and in the novel by Tiller. This article reflects upon, how students can identify with the main character, in terms of both categorical and situational empathy, and how the narrative situation can show the reader why the character's life unfolded as it did. The teacher must adjust the texts and the tasks to the particular group of students, and remember that teaching should not be a therapy session.

In 2014, The Norwegian Institute of Public Health (2014: 161) announced that about 20% of children and young people in Norway suffered from mental health problems that affected their daily lives. Statistics from 2018 show increasing numbers. Mental health is a key issue and many have argued that it should have a place in the Norwegian educational system. In 2016, The Ministry of Education and Research announced a revision of the national curriculum that would integrate 'public health and life mastery' into all high school subjects. Life mastery concerns how to live a good and healthy life, and how to function well in society. It is about life choices and their consequences for mental and physical health. Attitude, self-respect, sexuality and interpersonal relationships are keywords. The Ministry stated, that it is important to address life mastery because it has a close connection to the development of a learning community, psychosocial environment and prevention of bullying.

Medical humanities represent interdisciplinary cooperation between the humanities and healthcare. Central questions are how art can enhance patient care and healthcare professionals' knowledge about patients. The focus is on the clinical meeting between doctor and patient, where knowledge about personal experiences of illness can give the patient a stronger voice in the treatment (Bernhardsson, 2010). Narrative medicine is a field that focuses on the pedagogical perspectives of medical humanities. The aim is to train medical students to carefully listen, by learning to close read, in order to gain a more nuanced insight into an illness. Kaptein et al. (2018: 2) discuss, what reading novels can mean in the context of the medical humanities: "Novels *are an almost endless source of description of how patients, their family and friends, health care providers and society make sense of illness […]*". This makes one wonder, if novels can improve treatment, be therapeutic, and develop empathy. The focus has been on how art can contribute to medicine, but this article addresses how narrative medicine can supply the field of literature in high school. In this way, the article will demonstrate the meaningful transference of knowledge and methods between literature and medicine.

Gammelgaard and Boström (in publication) argue that the reason why mental illness is a well-known topic of fiction is that it is both a reaction to and a consequence of the meritocracy. Literature addressing mental illness can complement the traditional diagnostic process to include subjectivity and existential perspectives. In their textbook for Danish high school students, Gammelgaard and Boström aim to combine psychiatry, literary studies and pedagogy to show students how literature explores the mad mind and challenges the concept of normality. The aim is to teach students about different mental illnesses without being a textbook in psychiatry. However, Ekornes (2018) interviewed teachers about their health-promoting work. Many of the teachers said that it is important to shift focus from diagnosis, diseases and negatively charged vocabulary to well-being and health, not to pathologize students and to teach in a safe context. In narrative medicine, it is common to use texts that do not directly emphasize illness: "*It is arguably easier to teach non-medically inflected texts, since the clinical or illness-related dimensions of a text can sometimes deflect attention from considerations of form.*" (Charon et al., 2017: 183).

This article will discuss how the uses of fiction in a Norwegian educational framework can have the potential to create knowledge and dialogue about empathy, mental health and life mastery within the perspective of narrative medicine. I will illustrate Suzanne Keen's theory of narrative empathy through the Norwegian contemporary novel *Begynnelser/Beginnings* (2017)[1] by Carl Frode Tiller. Another research question emphasizes, how methods and insights from narrative medicine and the educational use of Norwegian literature can be brought together to teach high school students about mental health and life mastery. The article draws upon the thoughts of Bloom, van Lissa et al., Nussbaum and Bryant on empathy and its meaning. Suzanne Keen's theory of narrative empathy, with its focus on character identification and narrative situation (consonant and dissonant narration), will be used in the literary analysis of *Begynnelser.* Finally, the article will discuss how close reading, with the emphasis on attention, representation and affiliation, the keywords of narrative medicine, can be combined with narrative empathy and used in the high school classroom. The aim of this study is not empirical, but rather to reflect on how close reading can be implemented in the teaching situation and lead the way to increased empathy or at least raise important questions concerning health.

Perspectives on empathy

Empathy has no clear definition, and there is an inconsistency between the academic and the everyday use of the term. In the latter, empathy and sympathy seem to melt together as synonyms. An academic understanding is, that empathy means to observe and understand another's mental or emotional state. This involves setting one's own feelings aside, with the intention to feel and think like the other. Empathy is also about responding to someone's feelings. When we feel sympathy for someone, the focus shifts from the other to ourselves, and we imagine how we would feel in the given situation. It has been claimed, that sympathy rarely results in an act of caring that gives a significant meaning for the receiver (Wiseman, 1996). Professor of psychology Paul Bloom argues against empathy:

> *"Empathy is biased, pushing us in the direction of parochialism and racism. While empathy can motivate prosocial behaviour, […] it can also spark atrocities. Even when it is put to good use, empathic distress can be an ineffective motivator, as it can lead to burnout and exhaustion."* (2017: 25)

With this view, Bloom shows that empathy cannot be an exclusive good, which the broader discussion of empathy also shows. In the case of narrative medicine, it has been argued to depart from the concept of empathy to focus more generally on human interactions (Charon et al., 2017: 41). Bloom's argument, on the other hand, is a result of a quite specific understanding of empathy as an assumption of another's feelings. However, empathy involves more than this. I argue, that empathy could be a fruitful term to use, especially in a high school setting, precisely because of its ambiguity. The term demonstrates perspectives on human interaction that can be of significance for life mastery.

Nussbaum (2016) emphasizes how literature can stimulate ethical reflection. By reading, we challenge our prejudices and we are exposed to different perspectives. By entering the role of *"the judicious spectator"* (2016: 11), we can create a personal, yet distant connection to literature. As a reader, one can feel compassion but at the same time remain analytic and critical. This supports, the argument that reading fiction contributes to the development of empathy, which also involves the ability to create a balance between close and distant.

Are readers already empathetic or does reading promote empathy? Van Lissa et al. studied how the narrative perspective affects readers' empathy towards complex literary characters and found that *"[…] participants with greater dispositional affective empathy reported greater empathic concern for the protagonist. More experienced readers, on the other hand, reported less empathic concern for the character"* (van Lissa et al., 2016: 51). Even though, we cannot say that reading actually makes us more empathetic, we can say that it is a starting point for reactions and emotional responses and this can create conversations and discussions that lead to both knowledge and demonstrations of experience (Bernhardsson, 2010: 54).

According to Bryant (1987), empathy can predict mental health in children and adolescence. The empirical data shows that children with low reported empathy have a higher risk of mental health issues. Children showing high empathy are likely to develop stronger social relationships, and also to talk about and seek help to cope with their challenges. If one believes that empathy is teachable, high school students might be able to gain the same effects by learning to be more empathetic.

Narrative empathy

Suzanne Keen (2007) discusses the relations between reading novels and empathy. The theory of narrative empathy addresses how literary techniques manipulate reader responses and how reading can lead to shared feelings and mental simulation. Can we create conversations and discussions about mental health, life mastery and empathy in the classroom by using narrative empathy? Keen considers character identification and narrative situation as the two main techniques. Character identification is a complex process that takes place inside the reader based on the descriptions of characters, their qualities and skills and whether they are reliable. The character's goals, motives and behaviour can also be important for the identification. Keen argues, that the structure of the plot in a novel may help to make the reader identify with characters and that this can lead to the feeling of empathy. Hogan (2001) has divided empathy into two categories: categorical and situational. Categorical empathy is about identifying with people that are similar to oneself, in e.g. gender, age or ethnicity. Situational empathy, on the other hand, refers to having similar experiences as the person one is feeling empathy towards.

Research states, that a first-person narrator and an internal perspective have the best potential to create a close relationship between character and reader (Keen, 2007: 96-97). Van Lissa et al. (2016: 52) found that the narrative perspective did not have a great effect on an empathetic concern, but they *"[…] revealed that the third-person perspective engendered less perspective-taking than the first-person perspective for participants older than 17.44 and was not significant for younger participants […]"*. They also stated *"[…] it is legitimate to think that literary reading may help shape empathic competencies by exposing young readers to complex and […] ambivalent social situations"* (2016: 60). This argument is highly relevant for high school students.

Regarding the concept of narrative situation, the focus will be on consonant and dissonant narration. In consonant narration, the narrator has a close temporal link to the narrated story, for example through the present tense. In dissonant narration, there is retrospection and the narrator often judges or reflects on the narrated experiences. *"This kind of first-person narration may then contain sharply dif-*

ferentiated voices of the 'same' figure, the experiencing self and the retrospective self […]" (Keen, 2003: 36). This technique can be effective to show how, or if, the character matures.

Carl Frode Tillers' Begynnelser

I will now illustrate character identification and narrative situation, through the novel *Begynnelser* from 2017 by Carl Frode Tiller[2]. This novel is closely linked to the concept of life mastery, both in theme and structure. The book is about the first-person narrator, Terje, a Norwegian environmentalist, who is hospitalized after a suicide attempt. Through the novel, we follow Terje's life back in time, and we experience episodes from his adult life, his youth and his childhood. We witness a troubled boy, a tragic family story and a passion for the environment. Central themes in the novel are interpersonal relationships, life choices, existentialism and environmental problems. The timeline in the novel is backwards and shows how Terje's life develops from death to the beginning, reflecting the novel's title. The novel emphasizes, that life mastery is about seeing the personal and interpersonal consequences of the choices we make. We can also see the same expanded temporal aspect in the novel's structure as in the concept of life mastery. Mental illness, on the other hand, can be temporary and have a limited timeline, which can be fruitful to discuss with students.

Character identification

Terje's character can be difficult to comprehend. Throughout the novel, he reviews his life in retrospect and we learn that he has moved back into his mother's house after suddenly ending his marriage. He is often unsociable, rude and sarcastic. This has the potential to make the reader irritated, but the more one gets to know him, the closer one comes to understand the reasons for his behaviour. On the day before he leaves his wife, he wakes up in the middle of the night with a disturbing feeling: "*[…] it felt like my head was going to explode because of intense, white noise*"[3] (Tiller, 2017: 75). Terje experiences this several times and it even lingers when he feels happy (Tiller, 2017: 103) and in the hours before he drives in front of a lorry to kill himself (Tiller, 2017: 21). This white noise may indicate that he is losing control over his mind because he cannot sort out and process all the impressions from his emotions.

His wife, Turid, reacts badly to the breakup and takes it out on their daughter, Marit. In this situation, the reader's response can potentially shift because Marit is very important to Terje, and he is trying to be the father he never had himself, who left him and his family. The reader may now feel sympathy for Terje and anger towards Turid. Terje had a bad temper when he was younger, and he was sentenced to community service for physically assaulting two men for flirting with and insulting his girlfriend (Tiller, 2017: 246). The reader may identify with this provocation, but the shock of violence establishes Terje as a frightening and unpredictable character. Because of the reverse timeline, the reader knows that Terje has changed, at least on the outside. As an adult he is no longer violent. The reader understands, that he still gets angry but he expresses it in other ways, for example by being rude to the ones he loves. He turns his focus inwards and does not want anyone to know what he is thinking; slowly he loses himself to his thoughts.

Consonant and dissonant narration

Begynnelser starts with consonant narration, which implies a close temporal link between Terje's presence and the narrated story. Terje is in the hospital and finds that his mother and sister are in the room. This is a bodily experience at first; he opens his eyes, watching his family members. They cannot see that he is looking at them, and Terje starts to realize that he is dying. The name of the second chapter is *two days earlier* and from here the reader travels back in time through dissonant narration. This technique and structure functions as a search for reasons why Terje's life unfolded as it did, and opens up options of interpretation. Do we really have a choice, or is it simply nature vs. nurture? Terje chooses to break out of an unhealthy lifestyle, moving to another city to study. He creates a better life for himself but an inner struggle is still tormenting him. He knows that his behaviour hurts people around him but he is unable to say and do what he knows is right. For example, after a disagreement with his wife, she tells him that their life is going to get better. He understands that this is a situation where he can choose between right and wrong; his answer can actually help to make everything better. Despite this, he turns away from his wife, leaving her crying (Tiller, 2017: 181). Words are stuck inside him and he gets lost in his own mind.

Dissonant narration enables the first-person narrator to comment and reflect on situations. Terje does this in a shallow way, as if he is also shutting out the reader from his life. He digresses from the timeline to talk about the environment and these anecdotes create stories within the story. He is deeply passionate about the environment, and he loves his job as an advisor for nature conservation. He fears that humans will ruin the ecosystem. However, there is an underlying theme that nature will outlive humans, for example when he thinks about the saying t*o love one's neighbour* and how this should be expanded and applied to all the species on earth: "*[…] we should live in a way that the other species will miss us when our species is gone from the earth*" (Tiller, 2017: 214). This makes us realize, that he has hope, maybe not for humans but for nature.

As we approach the beginning of Terje's life, we understand that we are also witnessing his death. The stories within the story and the split narration and timeline melt together towards the end of the novel. As a child, he often imagined himself as an animal or that he entered the minds of other humans. The last episode of his retrospective narration is from the day his father left the family, which creates suitable tension. In this section, one wonders if the fantasy of being an animal is a childhood memory or if it is the present and the retrospective narration melting together to describe the experience of dying. Terje is becoming one with nature. His senses start to change, he alternates between being himself and other humans and insects and his hearing intensifies. He can hear the intense, crunching sound when his mother opens and closes her eyes. This can be a cue to the reader that this is from the consonant perspective, as hearing is said to be the last sense we lose before we die. The scene shifts from the childhood home to the hospital. He can see the seasons changing outside the window, from summer, the actual season of the childhood memory, to winter, the present time of his death. His mother's face changes from a young face to that of an old woman. Suddenly, Turid and Marit enter both his memory and the hospital room, but Terje does not understand this: "*[…] was that Turid and Marit entering, but how was that possible, I haven`t met Turid yet, I thought, and Marit hasn't been born yet*" (Tiller, 2017: 332). Then the childhood memory interrupts, allowing the reader to feel the tension in the narrative form and the tension between life and death. His father's voice appears, asking him if he is ready to go. Terje says he is ready because Turid and Marit have finally arrived. In the last lines of the novel, Terje becomes a sparrow and as he is flying, all the countries, the seasons, time, the human souls and the animal souls all become one under his wings. This is a picture of harmony, and in this we can find a glimpse of hope.

The narrative form allows the reader to see how everything is connected. This is done by small circular structures that can contribute to the readers' interpretation of why Terje's life turned out the way it did. A good example is the repeated dinner dialogue: Turid asks Terje what he would like for dinner. She is just being kind and caring but he answers her rudely. In the very last episode in the book, the exact same dialogue is repeated. This time Terje's father, in the same kind and caring way, asks Terje's mother what she wants for dinner. This indicates that a part of our behaviour is the result of inheritance. Terje's childhood was traumatic in many ways; he had to take care of his mother, whom suffered from depression and alcoholism and took it out on the rest of the family. Yet Terje starts to mistreat his own family, just as his mother did, and in the end, he also leaves his family, as his father left him. Another important repetition in the composition is when Terje ends his retrospective journey on the day his father left, parallel with the story of him leaving his own family.

Teaching narrative empathy with methods from narrative medicine

How can narrative medicine and the teaching of literature work together in a high school classroom to create knowledge and encourage conversations about mental health and life mastery through a focus on empathy? Complex texts are necessary to create discussion, but mental illness should not necessarily be the primary theme of the text. Reasons for this can be to prevent the pathologization of students and to avoid creating therapy sessions. Learning about mental health and life mastery is not about treating ill students or defining illness. It is about preparing the students for adulthood; enabling them to live an optimal life by taking care of themselves and others. A healthy state of mind is a combination and a balance between internal and external factors and empathy is an element that can be included in this discussion. However, the teacher must not become a therapist. The focus must be on how and why we respond to literature, and how we can experiment with being both analytically and personally involved in a text. *Begynnelser* is a dark novel in many ways, and the story involves suicide. Careful consideration is important before presenting this book in a high school classroom. On the other hand, the novel does not dwell on suicide and mental illness is not a direct theme. Terje has the potential to promote both categorical and situational empathy. He lives in a typical Norwegian society and in parts of the novel; he is at the same age as the students. The novel allows for situational empathy by appealing to the experience of growing up, learning about yourself and making the right, or wrong, choices. There are also social aspects of e.g. arguing or fighting with parents and friends. To prevent an overly personal connection to the topic one should focus on staying within the text. In this way, the students are actively working on text-analysis rather than e.g. self-diagnosing.

It is important to encourage high school students to see the link between experiences and emotional responses from fiction and their own behaviour in society and the world (Keen, 2007: xv). Charon and her colleagues developed narrative medicine with the intention to *"fortify healthcare with the capacity to skillfully receive the accounts persons give of themselves – to recognize, absorb, interpret, and be moved to action by the stories of others"* (Charon et al., 2017: 1). Attention, representation and affiliation are three keywords for narrative medicine. Attention is about maintaining a firm focus on listening to the one who is telling a story. Furthermore, this story needs to be uncovered and interpreted. The next step is to make a representation of this interpretation and present it to the teller. Affiliation is the result of attention and representation and involves the development of a union and cooperation between teller and listener, which will later lead to recognition and better care for the one who is ill (Charon et al., 2017: 3).

Narrative medicine is interdisciplinary but close reading as we know it from New Criticism is the main method: *"[…] close reading can bring readers to a fresh curiosity about and aliveness to what occurs in interactions between flesh and blood characters […]"* (Charon et al., 2017: 18-19). Close reading is transferable to real-life situations. The text is divided into sections and then into smaller pieces and fragments. The reader learns to pay attention to details such as verb tenses and descriptions, marking important passages in the text, reading aloud, listening to the pronunciation, and seeing textual connections. In addition to close reading, prompted writing and discussions are important. Empirical work by Charon, Hermann and Devlin (2016) show that close reading used in clinical settings enhances the quality of patient care. The method of close reading came originally from literary criticism and is, therefore, already familiar to teachers of literature. What is new, however, is the aim and focus from narrative medicine. This shows the fruitful transportation of elements between research fields that we can see in interdisciplinary cooperation, such as medical humanities.

The reading process in narrative medicine is set within a sociocultural context, often in reading circles, and students cooperate to combine personal and interpersonal interpretations by being aware of their own and other readers' responses. There is a hope that close reading can subsequently foster the ability to 'read' and understand the people we meet (Charon et al., 2017: 167). Thein et al. (2015) investigated the role of emotional rules in literature learning and interpretation. In reading circles, students are confronted with (in)attention and outlawed emotions, feelings that they might have avoided in more open settings. It is important for teachers to accommodate spaces where emotional rules can be disrupted.

> *"The goal of cultivating such spaces is not to accept all responses uncritically, but is instead to allow students to experiment with new ways of interacting with others and new ways of positioning themselves within these interactions, creating spaces for a wider range of discourses and interpretive possibilities to surface."* (Thein et al., 2015: 218)

Jurecic (2011: 24) is critical of the thought, that reading literature makes us more empathetic yet she claims that reading literature matters because it slows thought down and "*[…] provides a rare opportunity for sustained focus, contemplation, and introspection*". This is connected to uses of reading circles in the classroom, where the students can be invited to "*[…] dwell in uncertainty and to explore the difficulties of knowing, acknowledging, and responding to others*" (ibid.).

By finding and exploring situations in the world of fiction, one can identify different perspectives and then come to the realisation that stories can be 'thick': "*In other words, a gesture only exists within multiple relationships – to a particular moment, a particular person, and to other means of expression – and thick description begins to unpack such narrative elements.*" (Charon et al., 2017: 23). This relates to what Iser calls *indeterminacy* or *Leerstellen*, the opportunity for the reader to fill the gap. To be able to see these layers and nuances and to create room for interpretations, it is important to pay attention to a wide selection of narrative choices and not just focus on theme and plot (Charon et al., 2017: 48). The core of both narrative empathy and narrative medicine is the reader response and its implications for empathy and caring about others. In literature circles, high school students can learn to use the keywords of narrative medicine while reading. Attention is about learning to slow down and focus on what is really going on inside the text. Representation takes place when students together start to talk about and interpret the elements of the story to search for a deeper meaning. Through affiliation, the students can learn to see the implications of these insights on their own lives and relationships.

Begynnelser is a complex novel, both in its description of Terje and in its narrative form. The reader may feel anger towards Terje but perhaps also compassion for him. A close reading of Terje reveals, that he is not at all a flat character and the reader can see him maturing through the dissonant narration. Discussion prompts from this novel, in the spirit of narrative medicine and in a mental health and life mastery perspective could be e.g. to think of important life choices and their consequences, to reflect on forgiveness or the effect of how we use our everyday language. The teacher could also ask the students to think about something positive to do for the environment or encourage them to reflect on what is beneficial to life on earth.

Reading is an activity with great potential to evoke perceptions and strong emotions, regardless of theme. If one is addressing mental health in a classroom, one must also reflect upon certain ethical questions. It is important to know the students' background to be able to choose the right texts and to plan a session with a varied pedagogical approach that covers their circumstances and needs (Lauritzen & Nesby, 2016). In a narrative medicine context, Spiegel and Spencer write: "*In any setting we remain hypervigilant about privacy and do not probe into personal experiences, nor do we set any expectations for self-disclosure*" (Charon et al., 2017: 45). Giving the students a chance to read the text and note down a few words on their response beforehand can also be a good idea to prepare them for what is coming and give them a chance to inform the teacher if they think the exercise is going to be too difficult.

Conclusions: Bridging disciplines

This article illustrates narrative empathy through the novel *Begynnelser* (2017) by Carl Frode Tiller. The character identification of the main character, Terje, has the potential to create both categorical and situational empathy. The narrative situation complements this identification, and through consonant and dissonant narration, students can learn about Terje's life and reflect upon why things turned out as they did. Empathy may predict the development of social relationships and the ability to talk about problems. Insights from the bridging of narrative medicine and the teaching of Norwegian literature suggest that the close reading of fiction, with a focus on attention, representation and affiliation, may lead to a better understanding of people around us. The sociocultural aspect is important, and teachers must adjust the texts and tasks to the particular group of students.

This article aims to contribute to the educational debate on how public health and life mastery can become an interdisciplinary topic in high school and more specifically how Norwegian teachers can integrate the topic in Norwegian literature classes in a responsible and safe way. Further research on teaching methodology is required and action research can be a fruitful approach to provide empirical data in this connection.

Notes

1 The novel is not translated into English. The direct translation is *Beginnings*, but I will use the original title throughout the article.

2 Carl Frode Tiller (1970) is a Norwegian author who achieved a breakthrough in 2007 with the novel *Innsirkling*. His books have been acclaimed for their complex structures and convincing character descriptions.

3 The novel has not been translated into English, so the quotes from the novel are my translations.

References

Bernhardsson, K. (2010). *Litterära besvär - Skildringar av sjukdom i samtida svenske prosa*.Ellerströms.

Bloom, P. (2017). »Empathy and Its Discontents«, in T*rends in Cognitive Sciences. Vol. 21. No. 1.* https://doi.org/10.1016/j.tics.2016.11.004

Bryant, B. K. (1987). »Mental health, temperament, family, and friends: perspectives on children's empathy and social perspective taking«, in *Empathy and its development*, Eisenberg, N & Strayer, J. (ed). Cambridge University Press.

Charon, R. DasGupta, S. Hermann, N. Irvine, C. Marcus, E. R. Colón, E. R. Spencer, D. & Spiegel M. (2017). *The Principles and Practice of Narrative Medicine*. New York: Oxford University Press.

Charon, R. Hermann, N. & Devlin, M. (2016). »Close Reading and Creative Writing in Clinical Education: Teaching Attention, Representation, and Affiliation«, in *Academic Medicine. Vol 91, iss 3.* https://doi.org/10.1097/ACM.0000000000000827

Ekornes, S. (2018). *Lærerprofesjonalitet i arbeidet med psykisk helse i skolen*. Bergen: Fagbokforlaget.

Gammelgaard, L. & Boström, T. S. (2019). *Galskab i litteraturen*. In publication. Systime A/S.

Jurecic, A. (2011). »Empathy and the Critic«, in *College English. Vol. 74, iss. 1.*http://www.jstor.org/stable/23052371

Kaptein, A. Hughes, B. Murray, M. & Smyth J. (2018). »Start making sense: Art informing health psychology«, in *Health Psychology Open. Vol. 5, iss 1.* https://doi.org/10.1177/2055102918760042

Keen, S. (2007). *Empathy and the Novel*. New York: Oxford University Press. https://doi.org/10.1093/acprof:oso/9780195175769.001.0001

Keen, S. (2003). *Narrative Form*. London: Palgrave Macmillian. https://doi.org/10.1057/9780230503489

Lauritzen, L. M. & Nesby, L. (2016). »Selvbiografiske sykdomsskildringer i videregående skole«, in *Norsklæraren. Vol. 4*.

Nussbaum, M. C. (2016). *Litteraturens etikk - Følelser og forestillingsevne*. (Utvalg og innledning av Irene Engelstad. Oversatt av Agnete Øye). Oslo: Pax Forlag.

The Ministry of Education and Research (2016). Meld. St. 28 (2015-2016): F*ag - Fordypning - Forståelse - En fornyelse av Kunnskapsløftet*. URL: https://www.regjeringen.no/no/dokumenter/meld.-st.-28- 20152016/id2483955/?ch=1&q=

The Norwegian Institute of Public Health (2014). *Folkehelserapporten 2014 - Helsetilstanden i Norge*. Oslo, NO: Folkehelseinstituttet.

Thein, A. H. Guise, M. & Sloan, D. L. (2015). »Examining emotional rules in the English classroom: A critical discourse analysis of one student's literary responses in two academic contexts«, in *Research in the Teaching of English. Vol. 49, iss. 3*. http://works.bepress.com/meguise/5/

Tiller, C. F. (2017). *Begynnelser*. Oslo: Aschehoug.

Van Lissa, C. J. Caracciolo, M. Duuren, T. V. Leuveren, B. V. (2016). »Difficult Empathy. The Effect of Narrative Perspective on Readers' Engagement with a First-Person Narrator«, in *DIEGESIS. Interdisciplinary E-Journal for Narrative Research. 5.1*, 43-63. URL: https://www.diegesis.uni-wuppertal.de/index.php/diegesis/article/download/211/304

Wiseman, T. (1996). »A concept analysis of empathy«, in *Journal of Advanced Nursing. 23,* 1162 -1167. https://doi.org/10.1046/j.1365-2648.1996.12213.x

Originalartikel

‘Human First’: Teaching close reading and creative writing to medical students

Presentation of a new narrative medicine course in Denmark – and a review of the literature assessing the empirical evidence for the utility of such courses

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The University of Southern Denmark has introduced a mandatory course in Narrative Medicine into the curriculum of undergraduate medical students. It is part of a trajectory called ‘Human First’, which aims to improve the students’ empathic abilities by teaching them narrative compe-tencies to draw on in their future clinical encounters as medical doctors. Although, theoretical accounts seem to make a strong case for the utility and value of educational interventions, such as courses in narrative medicine or medical humanities, *there has been a lack of empirical studies providing evidence to support such accounts – especially those focusing on the longterm effects and impact on patient care. Our systematic literature search and review of empirical studies regarding the effects of teaching close reading of fictional texts and creative writing to medical and health care students, tentatively confirmed previous indications of positive effects. Larger, multisite and more rigorous studies that assess the long-term impacts of these educational interven-tions and adjust for local variations are, however, still in short supply. Finally, we present critical reflections on whether empathy and similar phenomena are at all measurable and discuss the possibility of meaningfully evaluating the utility of curricular interventions such as narrative medicine courses.*

Introduction

The humanities and health sciences share a common interest in the human condition. The two domains thus complement each other in ways that deepen our understanding of phenomena like birth, health, illness, and death. As an example, consider the case of a person suffering from a life-threatening disease. Knowledge from the medical field can result in treatments providing either recovery or a prolonged lifespan, and/or perhaps simply symptom alleviation. Literature and visual arts, on the other hand, may provide insight into the human experience of falling ill, of knowing death is immanent, or of recovering from disease, and help us understand how such a process affects personal identity and social relations.

In this article, we will narrow our focus within the health sciences and humanities, to the interdisciplinary field of medicine and literature. Modern day medical students often spend a large amount of their study time gaining knowledge about the functions and physical composition of the human body and how it may be healed after illness. This knowledge is the foundation for their ability to provide adequate healthcare to future patients. However, future physicians also need the ability to communicate well with their patients and build a relationship of trust, in order to make the patients feel safe and comfortable enough to disclose health problems and to increase their adherence to treatment.

Narrative Medicine is the practice of medicine with a *narrative competence*, understood as *"the ability to listen to the narratives of the patient, grasp and honour their meanings, and be moved to act on the patient's behalf"* (Charon, 2001). As a transgressing discipline, Narrative Med-icine was established at Columbia University in 2000 by Rita Charon, a professor of internal medicine with a PhD in English literature. Prior to the emergence of this discipline, scholars such as Kathryn Montgomery Hunter, a professor of literature, had been arguing for some time for enhancing the practice of medicine with a 'narrative knowledge' (Hunter, 1991). In terms of education, a 'narrative competence' is more aligned with the current principles of learnings goals at universities. Courses in Narrative Medicine have since then been taught to medical and health care students at Columbia using the literary methods of close reading and creative writing, which includes group reflections, interpretations, and discussions. The specific combination of close reading of socalled high literature and creative writing "in the shadow of" the readings is unique for Narrative Medicine as it seeks to enhance the clinical skills of listening. The courses at Columbia have, in recent years, inspired a number of universities to set up courses in Narrative Medicine or in the overlapping, but broader, field of Medical Humanities. Courses in Medical Humanities or Narrative Medicine are now found both in North America, Europe, the Middle East, South America, and Asia (Abdel-Halim & Alkattan, 2012; Acuna, 2003; Chun & Lee, 2016; Elcin et al., 2006; Gupta & Singh, 2011; Shankar, 2013). Medical Humanities covers disciplines such as History, Anthropology, Theology, Psychology, and Philosophy – as well as Cultural Studies, Film, Art, Theatre, Music and Literature. A course in medical humanities can include reading of literary texts, although these readings are not necessarily rigorous close readings followed by spontaneous creative writing. Literature per se is not even a sine qua non in a course in narrative medicine. The methods of close observation and creativity may also be applied to art, theatre, film, or music.

It is often assumed, that a medical doctor who understands both biomedical functionality and the manner in which her patients experience their conditions, may provide better care because each patient's specific circumstances and values are taken into account. The theoretical underpinnings established by researchers from Narrative Medicine – and Medical Humanities – have made this a sensible hypothesis; and in recent years, researchers have begun to investigate this proposition empirically.

This article is an exposition with several subsections. We begin by describing a new mandatory course in Narrative Medicine for undergraduate medical students at the University of South-ern Denmark. Then, we consider possible obstacles in regard to mapping the effects of teaching such courses, including the selection of outcome measures employed to investigate this, and even the fundamental question of the capacity of empirical evidence to support theoretical propositions. In an attempt to answer these questions, we continue with a review of empirical studies regarding the effects of teaching interventions for medical students employing close reading of literature and creative writing exercises. We conclude by offering our perspectives on the measurability of the clinically relevant skills intended to be developed and strengthened by such courses.

The Narrative Medicine Course at SDU

Since 2017, the University of Southern Denmark (SDU) has offered a six week long mandatory course in Narrative Medicine for first-year medical students, as well as a six week long elective course for graduate health care students. The mandatory course for medical students is the first of three small courses taught by scholars from humanities and medical science; the two subse-quent courses are Health Psychology and Medical Ethics, each of which count two ECTS points. The course(s) prepare the medical students for their first academic encounter with a person with one or more chronical illnesses. Each individual student meets a patient in his or her own home thrice during a short period of time. The student reflects on the meeting in a short piece of writing, which is read by and discussed with a nurse with extensive knowledge of the patient and with fellow medical students, supervised by the same nurse. During the first lecture of the narrative medicine course, one of these nurses is present and excerpts from one student's writing is presented.

SDU's new trajectory is named 'Human First', thereby signalling a subtle change in point of view from a biomedically based patientcentred care to a narratively based care of a human being; i.e. a person with a life story first, and a patient in the health care system second. There are several considerations behind this initiative. First of all, it is considered desirable by the Faculty of Health Sciences for the students to meet a chronically ill person early in their education and thereby cultivate their attitudes to 'the human condition'. Secondly, this approach includes providing the students with an opportunity to meet the person in his/her own home, and not in a hospital, thereby reducing, or even reversing, the hierarchic aspects of the relationship between doctor and patient. Finally, the approach is intended to encourage critical reflections on the traditionally stern distribution of authority between doctors and nurses in clinical practice. This intention is sought achieved by appointing a nurse, rather than a physician, as the medical student's primary contact person and facilitator in regard to the short, written reflections.

This trajectory is not completely unique among universities in Denmark, yet no other Danish university has introduced a *mandatory* course in *narrative medicine*. The Universities of Aarhus and Copenhagen have *elective* courses in medical humanities, specifically focusing on ethical di-lemmas of medical treatment represented in literature and film, and placed near the end of the education. By making the course in narrative medicine at SDU mandatory in undergraduate medical education, a narrative competence becomes integrated as part and parcel of the education. Yet, it might be preferable if the students at SDU were able to select an additional course in narrative medicine during their postgraduate years, since knowledge and competences are typically built up through repeated training over time. Further, students may be more receptive to fictional accounts of illness once they have experienced authentic accounts in the clinic during their undergraduate education. Even the three, relatively long meetings with a chronically ill person may change their idea about how people live with their illness.

The mandatory, six-week course in narrative medicine consists of lectures for 150 medical students in an auditorium interspersed with two sessions of 4 simultaneous seminars for approximately 40 students. In the four lectures, scholars from literature and medicine teach theoretical issues of principles and methods in narrative medicine, such as, how to define and measure physician empathy, and the importance of understanding patients' life stories. In the two seminars, scholars from literature teach close reading of short literary texts followed by spontaneous writing.[1]

The hypothesis of transferability of skills

The approach to narrative medicine at University of Southern Denmark is committed to a hypothesis, expressed by MD and Associate Professor in English literature Rishi Goyal as follows; *"the ability to read a book, a poem or a short story is similar to the act of listening well, and by training in the one, reading and writing, you can improve the other, listening and acting"*(Rasmussen & Goyal, 2017). Goyal is trained in the Narrative Medicine program, and he now teaches medical topics at the Department for Comparative Literature at Columbia. He was appointed Adjunct Associate Professor of Narrative Medicine at University of Southern Denmark in 2018. Rita Charon, the Executive Director of the program in Narrative Medicine, supports the idea of transferability of skills, noting: "*Students trained in close reading have been known to apply it to diverse sorts of texts and thus to discover things they would not otherwise have noticed […] If close reading helps persons to discover things they would* *not otherwise have noticed, perhaps it might help clinicians to notice what their patients try to tell them"*(Charon et al., 2017, 164-165).

Close Reading

The principles, methods, and pedagogical practice that direct the new Danish courses in narrative medicine are very much inspired by Columbia's model developed since 2000 (Charon et al., 2017). The medical students are introduced to the method and practice of close reading and to creative writing in the shadow of these readings. Close reading, as understood by Rita Charon, is a systematic and attentive reading of a given literary text in every detail so that the spoken as well as the unspoken in a narrative is elicited (ibid., 157-179). By 'systematic' is meant a relatively objective approach that guides a comprehensive analysis of the textual details, which then leads into a subjective interpretation. This kind of slow and almost absorbing readings of literature, which typically result in unpredictable and perhaps ambiguous conclusions, is foreign to most of the medical curriculum. Medical students read a lot of biomedical literature in order to memorize the important information and learn how to reduce complexities to unambiguous results. Close reading is almost the exact opposite of this as it contrasts a positivist approach with a hermeneutic one. One needs to pay attention to every sentence and every word in the, often short, fictional texts because an understanding of a complex narrative is reached through the totality of details, and these details are likewise understood through the text as a whole (Brockmeier & Meretoja, 2014). Close reading often invites the students to reflect upon their recognition of patients' stories, either through what professor of literature Rita Felski calls *"self-intensification"* or *"self-extension"* (Felski, 2008). In the first case the student mirrors herself in the character, in the second the student finds a universal relation to the foreign experience. By these kinds of recognition, the students access vital human knowledge of the self and others through close reading.

The students mostly read short, diverse texts of Danish literature, which all thematize illness and meetings with the health care system, collected in an anthology, *Ill literature [Syg litteratur]* (Mai & Simonsen, 2017). The reason why all texts thematize illness is purely pragmatic. One does not need to read a text about illness in order to practice close reading. One could even argue that reading texts about illness disturbs the medical students' attention to the fully human condition of life, love, friendship, fear, loss, and death. Yet, literature and art in general is so foreign to the (bio)medical curriculum that reading texts without any medical themes might cause disinterest.

The training in attention to, and understanding of, how details and whole are related as well as recognition of self and other, is – according to the hypothesis in narrative medicine – similar to the act of listening well to a patient account in the clinical practice. The clinician needs to revise her total understanding of an illness narrative, if new information is given by the patient, and this information is always founded in a larger, sometimes hidden, narrative, which can often be cate-gorized as a diagnosis. Likewise, the suffering and fear of the patient should be recognized as a foreign, though not completely unintelligible, experience.

Creative Writing

Adding creative writing as an imaginative discovery to the close reading of a fictional text, has been described, by writer of fiction and teacher in narrative medicine at Columbia, Nellie Hermann, to increase the likelihood that a medical student understands herself and others as vulnerable individuals and as participants in a trustworthy group rather than a competitive class (Hermann, 2017, 211-232). Students are requested to write creatively to a prompt, which must be open in its formulation, so that everyone can find their own imaginative path when answering it. Students are always requested to write ‘in the shadow of’ the reading, which means that the exercise takes its point of departure in the close reading of a text. Afterwards, the students are requested to share their writing with each other in pairs, and then – if anyone has the courage – to share it with the entire group of students. By writing a text on their own, even if this only lasts for five to seven minutes, each student is confronted by her own thoughts, feelings, and imagination. This spontaneous act of writing is often experienced as a process of deeper self-understanding and, perhaps, improved empathy with fellow students. By sharing the written text with others, the texts often grow in importance to the individual student and the other students gets access to something vulnerable and personal in their fellow students, which is rarely accessible in a classroom. Through these intimately related rigorous methods and pedagogical practices, narrative medicine can potentially foster a narrative competence, including narrative empathy and selfcare, in medical and health care students.

Declining empathy during medical education years?

In 2011 Melanie Neumann and her colleagues published the systematic review "Empathy Decline and Its Reasons", which finds that the level of empathy among medical students declines throughout medical education (Neumann et al., 2011). The authors reviewed studies investigating changes in trainees' empathy levels and sought to pinpoint possible reasons for those changes during medical school and residency. The decline of empathy in the present health care system is assumed to begin in the medical education when the medical students turn their minds to memorizing anatomy or biochemistry, or when then, learn how to dissect a corpse, and thereby start to translate their knowledge and competences into a detached, scientific medicine. Ill persons become patients, listening to stories becomes listening for anamneses, the richness of psychological experience is reduced to psychiatric diagnosis and medical treatment.

As a contrast, the ideal of narrative empathy in health care can be defined as a *"full, non-judgmental, generative reception [of an illness story] that is informed by all aspects of what a teller tells – in words, silences, gestures, position, mood, prior utterances. The attentive listener absorbs what is given and can then* return *to the teller a representation of what was heard"* (Charon, 2017, 157). Professionalism might be understood as: Paying attention to the patient's chief complaint as well as the person's chief concern (Schleifer & Vannatta, 2013). A Danish professor of medicine has defined the ideal as *"the skill to shift between on the one hand distancing analysis of symptoms and clinical signs and on the other hand an empathetic recognition of ill persons emotions, idiosyncrasies and decision making"* (Hrobjartsson et al., 2013).

The concept of empathy is, of course, debated in and across academic disciplines, especially in medicine and the medical humanities.[2] Literary scholar Suzanne Keen works with a notion of narrative empathy which she defines as, "… *the sharing of feeling and perspective-taking induced by reading, viewing, hearing, or imagining narratives of another's situation and condition.*" (Keen, 2013, [2]).

In Neumann et al.'s study, empathy is considered a key element of patient-physician communication that positively influences patients' health. The study treats empathy as a feature, which is learned in childhood and – unintendedly – unlearned during medical education. Vice versa, empathy can be (re)learned in higher education through reading of for example literature as argued most prominently by the philosopher Martha Nussbaum (Nussbaum, 1997)[3] . For Nussbaum, reading great literature especially from foreign cultures and historical epochs stimulates a 'narra-tive imagination' of basic human conditions, comparable to Rita Felski's concept of recognition as 'self-extension'.

One proposed solution to counter the suggested empathy decline in medical education, is introducing courses, which train students in narrative virtues common in the humanities, i.e. close reading of literature, film, art etc. and creative writing. Teaching courses in narrative medicine – or medical humanities – has been shown to correlate with increases in their empathy levels; improved capacities for reflection; better communication skills and ability to create a committed partnership, or affiliation, with their patients (Charon et al., 2016). Improvements in these abilities and skills have in turn been suggested to result in more attentive and empathic clinical care (ibid.). However, only very few studies have investigated the *long term effect*s and *impacts on patients' health and well-being*, as a result of teaching such courses to medical students (Ousager & Johannessen, 2010).

Important questions

One explicit ambition with the initiative 'Human First' at University of Southern Denmark, is to prevent the decline in empathy and the narrowing of professional focus among medical students during their education – and instead sustain, and maybe even increase, their empathy levels and understanding of the complexity of human narratives. With such an ambition, certain questions become of great importance: How can one measure *if* a mandatory course in narrative medicine contributes to students understanding of the narrative aspects of medical care? What are the pros and cons of qualitative and/or quantitative methods, and can we imagine a longitudinal measuring of increase in empathy correlated with courses in narrative medicine? Another important ques-tion is whether improved empathy should be the only parameter of success for courses in narrative medicine or medical humanities. Perhaps empathy should simply be one parameter among others like curiosity, creativity, wisdom, and self-care, which are also very difficult to measure – if not irreducible to measurement.

Literature review

To investigate the current state of knowledge on the effects of teaching close reading and doing writing exercises with students of health care, we conducted a search and review of the academic literature. In the following, the procedure and results are presented in narrative form.

Aim and scope

The aim was to identify literature describing and investigating what possible impact teaching close *reading* and doing *writing exercises* with *health care students* might have on the students. Our re-search question thus read:

Which effects result from teaching students of health care close reading of literature followed by writing exercises?

Method

To identify key terms relating to the research question, five articles, which we regarded as central to our aim (Shannon L Arntfield et al., 2013b; Devlin et al., 2015; Miller et al., 2014; Pfeiffer et al., 2016), were carefully reviewed. A list of key terms, collected during the reviewing of the five articles, was discussed, shortened and reviewed until it contained only terms which we both agreed were key terms for this review. These terms became the foundation for our initial choice of search terms. The discussion also made it clear, that the original research question needed more precision, if it were to guide the review process properly. Therefore, we developed the following ex-tended research question:

Which *(measurable, possibly positive, long or short term)* ***effects*** *(particularly regarding the stu-dents' development professionally, personally and in terms of abilities to communicate, collaborate, be empathic, compassionate, and patient-centred, aware of ethical concerns, shift perspectives, be atten-tive, think critically, and reflect)* ***result from teaching students of health care close reading of literature*** *(e.g. fiction, biographies, pathographies, etc.)* ***followed by writing exercises*** *(e.g. creative writing)?*

Guided by the extended research question, we were able to create a comprehensive list of search terms and combinations using the PICO-framework[4] – a scheme for clarifying the population, intervention, comparison, and outcome of interest (Scells et al., 2017). The following is an abbreviated presentation of our PICO:

- **P**opulation: Students of any health care field (e.g. medicine, nursing, etc.) in any part of the world.

- **I**ntervention: Education (e.g. a course or workshop) in 'medical humanities', 'narrative medicine', or any other teaching described which applies literature reading and writing exercises.
- **C**omparison: Absence of the education described as the intervention.
- **O**utcome: changes in empathic abilities, communication skills, collaboration skills, perspective taking, critical and creative thinking, social awareness etc.

Unfortunately, using the comprehensive list of search terms in the database searches, returned far more entries than would be possible to read through within the timeframe available. The review thus had to be greatly restricted in scope which is a clear drawback on the side of evidential strength (compared to e.g. a full systematic review). Conversely, the review contributes both through its *methodological example* (which others may build on and expand upon), and through the appraisal and discussion of the studies included, which give a provisional account, of the current state of knowledge on the effects of teaching close reading and doing writing exercises with students of health care.

Search process

We searched five databases: ERIC, PubMed, Embase, Medline, and Scopus. Studies in *any language* would be included as long as an English abstract was available. We searched for studies with *publication date*s from the earliest available date in each database and up until December 31st 2017. The search was limited to include only *peer reviewed* publications to ensure scientific rigour.

After conducting a number of search trials to evaluate the size and scope of the returns, two combinations of search terms were selected: "medical humanities AND student*", and "narrative medicine AND student*", with the '*' indicating the use of truncated versions of the term 'student'. These combinations were deemed sufficiently *broad* to capture a large number of studies of relevance to this review, and still sufficiently limited to make the review task possible within our time frame. In addition to this systematic, albeit *limited*, search, we included any relevant studies from other reviews on similar topics, and also did hand searches of the literature lists of our five basis-documents.

Selection criteria

Inclusion criteria:

- Published (and not retracted)
- Peer-reviewed
- Empirical studies (of any design type)
- Population is health care students
- Students have taken at least one course in "narrative medicine", or a medical humanities course described as including close reading and writing exercises.
- Some *specific outcome* was examined, such as e.g. changes in empathy scores, improvements in collaboration, or improved critical thinking.

Exclusion criteria:

- Languages other than English, Danish, Swedish or Norwegian
- Studies with only preliminary results (e.g. conference abstract)
- Reviews

Relevant reviews were hand searched for additional studies.

Selection process

After limiting our scope, searches in the five databases yielded a total of 832 titles. All references were imported into Endnote, and after duplicate removal (including one translated article), a total of 286 titles remained. The first sorting, which was done at the abstract level, excluded a total of 255 titles. Of the 31 articles selected for full-text review, 10 studies were found eligible for the review – including one of our basis-documents (Shannon L Arntfield et al., 2013b). Through our initial searches, and via our basis-documents, we identified three literature reviews relevant for our aim (Barber & Moreno-Leguizamon, 2017; Batt-Rawden et al., 2013; Wieżel et al., 2017), which we also checked for eligible studies. This yielded an additional seven studies (DasGupta & Charon, 2004; Lancaster et al., 2002; Muszkat et al., 2010; Rosenthal et al., 2011; Johanna Shapiro et al., 2004; Johanna Shapiro et al., 2006; Tsai & Ho, 2012). In total, we ended up with 17 studies to include in our review. The full process is depicted in the flow chart below (figure 1).

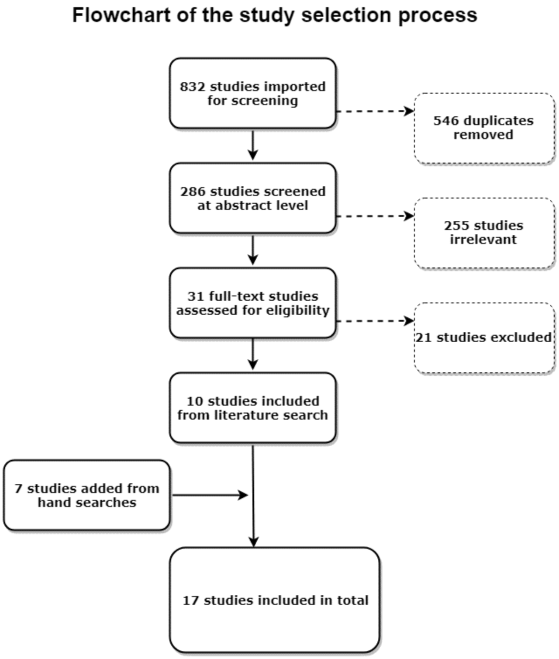

Figure 1:

Results

Among the 17 included studies, 15 were in the field of medicine, one was in pharmacy, and one was health care broadly. Ten of the courses were mandatory – either specifically, or in the sense that students had to choose among various medical humanities courses offered. Three of the studies included first year students, two targeted students in their second year, seven studies were among third year students, and three studies included fourth year students. Two of the studies did not specify student year. An overview of the results can be found in table 1, presenting included studies and their characteristics.

Reference	**Population** (field, participants, year)	**Course type**	**Outcome measures** (self-reported / other: •)
Arntfield et al. (2013)	Medicine, n=12, third year	Elective	Self-reported

Chretien et al. (2015)	Medicine, n=47, third year	Mandatory	Self-reported
Cunningham et al. (2017)	Medicine, n=97, first year	Mandatory	Self-reported
DasGupta & Charon (2004)	Medicine, n=11, second year	Elective	Self-reported
Garrison et al. (2011)	Medicine, n=46, third year	Mandatory	Self-reported
Graham et al. (2016)	Medicine, n=68, pre-clinical (25 in intervention group)	Elective	• Jefferson Scale of Empathy Student Version (JSE-S)
Lancaster et al. (2002)	Medicine, n=5, fourth year	Elective	Self-reported
McDonald et al. (2015)	Medicine, n=6, third year	Elective	Self-reported
Muszkat et al. (2010)	Medicine, n=44, fourth year	Mandatory	Self-reported
Patterson et al. (2016)	Medicine, n=141, first year	Mandatory	Self-reported
Rosenthal et al. (2011)	Medicine, n=209, third year	Mandatory	• Jefferson Scale of Physician Empathy Medical Student Ver-sion (JSPE-MS)
Shapiro et al. (2004)	Medicine, n=16, first year	Elective	• Balanced Emotional Empa-thy Scale (BEES) • Empathy Construct Rating Scale (ECRS) • Focus group interviews

Shapiro et al. (2005)	Medicine, n=82, third year	Mandatory	Self-reported
Shapiro et al. (2006)	Medicine, n=92, second year	Mandatory	• Theme frequency • Linguistic Inquiry and Word Count (LIWC) • Objective Structured Clinical Examination - Standardized Patient (OSCE-SR) Ratings.
Shapiro et al. (2016)	Medicine, n=595, third year	Mandatory	• Qualitative thematic analysis of students' creative projects.
Tsai & Ho (2012)	Health care, n=54, N/A (15 in intervention group)	Elective	• Objective Structured Clinical Examination (OSCE) Scores
Zimmermann (2013)	Pharmacy, n=52, fourth year	Mandatory	Self-reported

Table 1: Included studies

Review of included studies

Eleven of the studies included in this review rely on outcomes-based either on selfassessment by the participating students or on a thematic analysis of students' written material (Shannon L. Arntfield et al., 2013a; Chretien et al., 2015; Cunningham et al., 2017; DasGupta & Charon, 2004; Garrison et al., 2011; Lancaster et al., 2002; McDonald et al., 2015; Muszkat et al., 2010; Patterson et al., 2016; Johanna Shapiro et al., 2005; Zimmermann, 2013). The studies' analyses suggest that these healthcare students (with a majority of medical students) receive the narrative medicine courses well and find that they develop both personally and professionally. Examples of students' developments during a course include increased capacity for perspective-taking and improved ability to empathize, communicate and reflect critically.

These studies, however, have certain limitations, since selfassessments may suffer from reporting bias, and the thematic analyses of texts with no precondition comparison are not strong indicators that the courses play any causal role for their personal or professional development – even if they do. Thus, in the following, a more thorough presentation is given of the six studies included in this review, which rely either on validated measuring scales or other outcomes not requiring students to selfevaluate.

Graham et al. (2016) designed a study to assess whether medical humanities (MH) course-work correlated with superior empathy outcomes, as measured on the Jefferson Scale of Empathy Student Version (JSE-S). Measurements were taken before the MH course began, and after it was completed. The results showed a statistically significant difference between the group (n=25) that participated in a medical humanities course and the group that didn't (n=43). However, the researchers chose to differentiate between those whose scores declined or were unchanged and those whose scores improved. Had they shown the difference between decline, unchanged, and improved scores as three different outcome groups, it would have been interesting to see if the results would show similar statistically significant differences between the two groups. Also, since the group taking the MH course had elected to do so, it cannot be determined whether the increase in empathy scores was a result of the MH course, or simply because students whose empathy scores would increase were more likely to enrol in a MH course. Graham et al. acknowledge this possible bias, as well as the uncertainties of a small sample size. Nevertheless, their study is an important step towards larger and more robust studies of empathy in medical students and how it relates to taking medical humanities courses.

Rosenthal et al. (2011) did a before-and-after study measuring empathy scores of two consecutive classes of medical school students (n=209). During their clerkship, the students participated in an added, mandatory "Humanism and Professionalism" component. This educational intervention consisted of group discussions based on reflective articles and fiction as well as students' own writing posted on a blog after each clerkship. Students' empathy scores were measured using the Jefferson Scale of Physician Empathy Medical Student Version (JSPE-MS), before beginning clerkship and at the end of the clerkship year. No significant change in empathy occurred in either of the classes. In light of previous studies (Hojat et al., 2009; Newton et al., 2008) having shown trends of declining empathy levels among students in their third year of medical school, the authors interpreted this result positively, suggesting that the educational intervention had preserved empathy in these classes. Due to the lack of a directly comparable class, it cannot reliably be concluded that empathy was *preserved* as it could have remained unchanged regardless of the intervention. The study can, however, serve as inspiration for a fuller investigation of such courses' possible effects.

Empathy is a complex phenomenon, and Shapiro, Morrison and Boker (2004) decided to measure it by use of two scales corresponding to the distinction between **affective** and *cognitive empathy*. Medical students in their first year (n=16) enrolled in an elective course on medicine and literature, where they would discuss short stories during eight small-group sessions. Pre- and post-intervention measures were collected for the two empathy scales, and additionally for an attitudes-towards-the-humanities scale, as well as in qualitative group interviews. Results showed a significant *increase* in *affective empathy* scores (measured on the Balanced Emotional Empathy Scale, BEES (Mehrabian, 1996)), but *no significant changes* in *cognitive empathy* scores (measured on the Empathy Construct Rating Scale, ECRS (Monica, 1981)). The qualitative analysis of the group interviews suggested students had gained a better understanding of the patients' perspective, and how literature can help students cope with medical school. It also found that students' perceptions of 'empathy' had remained unchanged.

Shapiro, Rucker, Boker and Lie (2006) report on a comparative study of 92 preclinical medical students divided into two demographically matched groups, trained either in point-of-view (POV) writing (n=47) or in clinical reasoning (CR). Group differences were measured by theme frequency (comparing numbers for the presence/absence of 11 themes); by Linguistic Inquiry and Word Count (LIWC) (Pennebaker et al., 2001); and by Standardized Patient (SR) ratings from an Objective Structured Clinical Examination (OSCE). Thematic frequency analysis showed statistically significant ($p>0.1$) results such as the POV group scoring higher for the themes "Point of view", "Empathy for doctor" and »Feelings of doctor" – and conversely the CR group scoring higher for "Blame of patient" and "Preven-tion" themes. The LIWC analysis found more expression of feelings (and more feelings of anger) in the POV group, where students also made more references to spiritual and religious aspects. The CR group wrote longer sentences on average, used more technical words as well as sports analogies. Statistical analysis of the

SR ratings showed no significant difference between the two groups, meaning that those acting as patients at the OSCE were equally satisfied with both groups. The authors consider that the SR result may mean either that the *"empathic skills developed through writing may not translate into behaviour"* (p. 103), or that the translation is case-specific, or that training students in the preclinical phase means the empathic skills developed were misinterpreted as unprofessional or are perhaps just not appreciated as much by actor patients as they would be by actual patients in a clinical setting.

In a more recent paper, Shapiro, Ortiz, Ree and Sarwar (2016) qualitatively analysed the thematic and emotionbased dimensions in creative projects from students in their third-year paediatrics clerkship, during which they were trained in reflective writing. The study included 520 projects (representing 595 students) collected during a 10-year period. The authors found that students' projects suggest a patient-centred and empathic approach and that the *emotional* connection with patients and families was particularly valued by students. This study is an example of, how one can employ a humanistic approach in measuring outcomes, without resorting to selfevaluations. However, it is still possible that students were aware of how they represented themselves in their projects, which draws the conclusions closer to direct selfevaluations. The size (595 students) and duration (10-year period) of this study's material is a clear strength of this study, lending more weight to the authors' conclusion that *"students can use artistic media and narrative to insightfully interrogate their clinical experiences"* (p. 9).

Tsai and Ho (2012) aimed to investigate whether narrative medicine training could improve health care students' clinical performance. To measure this, they used scores of the Objective Structured Clinical Examination (OSCE) as a means of testing whether effects could be found at the behavioural level judged by others, rather than selfassessment. A large group of 116 medical interns were eligible for the study and were randomized to either being invited to taking a narrative medicine course, or not being invited to do so but remain in the study as controls. Despite the initially large group, only 15 students took part in the course and a sample of 39 students participated as controls. Tsai and Ho were able to match the two groups by age, gender, and academic performance, and together with the randomization, this is a clear strength for this study. They found statistically significant differences between OSCE-scores on the examinations' two communication stations, with the narrative medicine group scoring higher than controls, but no significant difference between the two groups' total scores for all 12 station tests. Given the small sample size and singular location, extrapolation of the results is not warranted. However, since OSCEs are widely used in health care educations around the world, repeating this study in various locations with larger samples might be a feasible path for obtaining results that are more straightforward to compare and compile.

Summary of findings

The studies included in this review all tend to endorse medical humanities courses based on their findings. However, as the researchers themselves point out, many of the studies have risks of bias as well as other limitations. The quantitative studies often lack in size to offer more robust findings, and many qualitative studies are based on course evaluations or student writings, which may offer valuable insights into student perspectives and preferences but cannot be used to establish any connection to improvements in clinical encounters with patients (even if they exist).

Discussion and limitations

Our literature review did not include grey literature, which may be a significant drawback as there is a chance of publication bias, since those investigating possible effects are often themselves invested in the field of medical humanities and may be teaching also. Further, although, the search and selection process was systematic, it had to be limited in scope, meaning that many more studies on educational interventions in medical humanities may exist, and together point to a different conclusion. There may also be publication bias within this field, since effect studies, so far, are mostly conducted at singular teaching facilities. Future research should aim for larger studies with multiple outcome measures – both quantitative and qualitative – and ideally, involve researchers from several health educations in different locations.

This review restricted its target population to students of health care, but it should be noted, that a number of studies can be found, which target the post-graduate group (i.e. health care professionals including medical doctors, nurses, etc.), and which have found beneficial effects of training in narrative competencies.

Finally, we wish to point out the very foundational challenge of measuring humanistic teaching interventions, and the concerns of some scholars who regard these measuring at-tempts as a mistaken application of natural science ideals and methods to an incompatible field – the humanities. In the next and final section, we will provide some perspectives on this discussion.

Perspectives on measuring effects of medical humanities courses

In a literature review (Ousager & Johannessen, 2010) by two scholars from the University of Southern Denmark investigating *"the extent to which the literature on humanities in under-graduate medical education seeks to provide evidence of a long-term impact of this integration of humanities in undergraduate medical education"* (p. 988), the authors found that only 9 papers, out of the 245 eligible for their review, were concerned with this issue. Researching the effects of curricular interventions generally poses serious methodological challenges due to, among other things, the large number of possible confounders. Investigating humanities courses in medical education may pose even imminent challenges since learning outcomes are usually not just about knowledge acquisition, technical applicability capacity. Instead, humanities courses often attempt to develop specific *abilities* (e.g. perspective-taking, reflection, critical self-assessment, etc.) and *valuable characters traits* (e.g. empathy, attention, curiosity, etc.) that are expected to support medical students in becoming 'better doctors'.

As exemplified above, the outcomes of humanities courses, and not least the theorized mechanisms for how they can contribute to making medical students better doctors, stem from a tradition which commonly seeks to understand a concept or phenomenon by expanding it and unfolding all its nuances rather than reduce it to simpler factors and understand it through its separate parts and their functions. This reflects, an often-noted difference between the biomedical and the humanistic approach to health care, and some will even argue that this divide shows us precisely why insisting on measuring outcomes and effects of teaching humanities courses to medical students is a futile endeavour[5] . But there is no reason why the two approaches cannot coexist within medical education. Associate Professor in medical humanities, Catherine Belling, wrote a critical comment to the aforementioned literature review and made a case for *"the importance of attention to linguistic irreducibility in the multiple texts of medicine"* (Belling, 2010, 939). For Belling, the *"humanities offer precisely what is missing in both blunt reductionism and fuzzy holism: incisive attention to specificity"* (Ibid, 940). If teaching humanities courses to medical students do have an overall positive impact on them as future doctors, this might be assessed via both rich and nuanced descriptions (as in the humanist tradition), as well as via reductionist outcome measures (as in the scientific tradition). The hard task is to pick the 'right' outcome measures to investigate, which is a matter of importance, feasibility of study, and effect size.

A course in narrative medicine like the one at University of Southern Denmark might have a short-term effect on students' 'narrative competence' to understand and recognize illness stories in the clinical practice, yet, a stronger effect might result if more plenum lectures were changed into small seminars, or if the mandatory course were followed up by an elective course later in their education.

Having healthier, more content patients may be the most important outcome, but surrogate outcome measures, such as higher levels of empathy (Graham et al., 2016) or higher OSCE-scores in communication (Tsai & Ho, 2012), may be needed to make the study feasible. Furthermore, health and happiness are in themselves subjective experiences, which can be evaluated in different ways depending on what is emphasized. Consider the following example: Although a long life is generally desired, a long life in pain may not be. And although physical pain is generally avoided, a life in physical pain may nevertheless be worth living for the individual who feels highly rewarded by close relations or a fulfilling vocation.

References

Abdel-Halim, R.E., & Alkattan, K.M. (2012). Introducing medical humanities in the medical curriculum in Saudi Arabia: A pedagogical experiment. *Urology annals, 4*, 73-79. https://doi.org/10.4103/0974-7796.95549

Acuna, L.E. (2003). Teaching Humanities at the National University of la Plata, Argentina. *Academic medicine : journal of the Association of American Medical Colleges, 78,* 1024-1027. https://doi.org/10.1097/00001888-200310000-00017

Arntfield, S.L., Slesar, K., Dickson, J., & Charon, R. (2013a). Narrative medicine as a means of training medical students toward residency competencies. *Patient education and counseling, 91*, 280-286. https://doi.org/10.1016/j.pec.2013.01.014

Arntfield, S.L., Slesar, K., Dickson, J., & Charon, R. (2013b). Narrative medicine as a means of training medical students toward residency competencies. *Patient Education and Counseling, 91*, 280-286. https://doi.org/10.1016/j.pec.2013.01.014

Barber, S., & Moreno-Leguizamon, C.J. (2017). Can narrative medicine education contribute to the delivery of compassionate care? A review of the literature. *Medical Humanities, 43*, 199-203. https://doi.org/10.1136/medhum-2017-011242

Batt-Rawden, S.A., Chisolm, M.S., Anton, B., & Flickinger, T.E. (2013). Teaching empathy to medical students: an updated, systematic review. *Academic Medicine, 88*, 1171-1177. https://doi.org/10.1097/ACM.0b013e318299f3e3

Belling, C. (2010). Commentary: Sharper Instruments: On Defending the Humanities in Undergraduate Medical Education. *Academic medicine : journal of the Association of American Medical Colleges, 85*, 938-940. https://doi.org/10.1097/ACM.0b013e3181dc1820

Brockmeier, J., & Meretoja, H. (2014). Understanding narrative hermeneutics. *Storyworlds: A journal of narrative studies, 6*, 1-27. https://doi.org/10.5250/storyworlds.6.2.0001

Charon, R. (2001). Narrative medicine: a model for empathy, reflection, profession, and trust. *Jama, 286*, 1897-1902. https://doi.org/10.1001/jama.286.15.1897

Charon, R. (2017). Close reading: The signature method of narrative medicine. *The principles and practice of narrative medicine*, 157-179. https://doi.org/10.1093/med/9780199360192.003.0008

Charon, R., DasGupta, S., Hermann, N., Irvine, C., Marcus, E.R., Colón, E.R., et al. (2017). *The Principles and Practice of Narrative Medicine*. US: Oxford University Press. https://doi.org/10.1093/med/9780199360192.001.0001

Charon, R., Hermann, N., & Devlin, M.J. (2016). Close Reading and Creative Writing in Clinical Education: Teaching Attention, Representation, and Affiliation. *Academic Medicine, 91*, 345-350. https://doi.org/10.1097/ACM.0000000000000827

Chretien, K.C., Swenson, R., Yoon, B., Julian, R., Keenan, J., Croffoot, J., et al. (2015). Tell Me Your Story: A Pilot Narrative Medicine Curriculum During the Medicine Clerkship. *Journal of General Internal Medicine, 30,* 1025-1028. https://doi.org/10.1007/s11606-015-3211-z

Chun, K.H., & Lee, Y.H. (2016). Improvement of debate competence: an outcome of an introductory course for medical humanities. *Korean journal of medical education*, *28*, 87-93. https://doi.org/10.3946/kjme.2016.13

Cunningham, H., Taylor, D., Desai, U.A., Quiah, S.C., Kaplan, B., Fei, L., et al. (2017). Looking Back to Move Forward: First-Year Medical Students' Meta-Reflections on their Narrative Portfolio Writings. *Academic medicine : journal of the Association of American Medical Colleges.* https://doi.org/10.1097/ACM.0000000000002102

DasGupta, S., & Charon, R. (2004). Personal illness narratives: using reflective writing to teach empathy. *Academic medicine, 79*, 351-356. https://doi.org/10.1097/00001888-200404000-00013

Devlin, M.J., Richards, B.F., Cunningham, H., Desai, U., Lewis, O., Mutnick, A., et al. (2015). »Where Does the Circle End?«: Representation as a Critical Aspect of Reflection in Teaching Social and Behavioral Sciences in Medicine. *Academic Psychiatry*, *39*, 669-677. https://doi.org/10.1007/s40596-014-0222-8

Elcin, M., Odabasi, O., Ward, K., Turan, S., Akyuz, C., & Sayek, I. (2006). The first medical humanities programme in Turkey. *Medical Education*, *40*, 278-282. https://doi.org/10.1111/j.1365-2929.2006.02390.x

Felski, R. (2008). Uses of Literature. *Malden: Blackwell*, 23-50. https://doi.org/10.1002/9781444302790

Garrison, D., Lyness, J.M., Frank, J.B., & Epstein, R.M. (2011). Qualitative analysis of medical student impressions of a narrative exercise in the third-year psychiatry clerkship. Academic medicine : *journal of the Association of American Medical Colleges, 86*, 85-89. https://doi.org/10.1097/ACM.0b013e3181ff7a63

Graham, J., Benson, L.M., Swanson, J., Potyk, D., Daratha, K., & Roberts, K. (2016). Medical Humanities Coursework Is Associated with Greater Measured Empathy in Medical Students. *The American journal of medicine, 129*, 1334-1337. https://doi.org/10.1016/j.amjmed.2016.08.005

Gupta, S., & Singh, S. (2011). Confluence: Understanding medical humanities through street theatre. *Medical Humanities, 37*, 127-128. https://doi.org/10.1136/jmh.2010.006973

Hermann, N. (2017). Creativity: What, Why, and Where? *The Principles and Practice of Narrative Medicine*: Oxford University Press. https://doi.org/10.1093/med/9780199360192.003.0010

Hojat, M. (2016). *Empathy in Health Professions Education and Patient Care*. Cham: Springer International Publishing. https://doi.org/10.1007/978-3-319-27625-0

Hojat, M., Vergare, M.J., Maxwell, K., Brainard, G., Herrine, S.K., Isenberg, G.A., et al. (2009). The Devil is in the Third Year: A Longitudinal Study of Erosion of Empathy in Medical School. *Academic Medicine, 84*, 1182-1191. https://doi.org/10.1097/ACM.0b013e3181b17e55

Hrobjartsson, A., Skydsgaard, M., Wielandt, H., & Graugaard, C. (2013). Lægekunst. *BIBLIOTEK FOR LÆGER, 205*, 332-333.

Hunter, K.M. (1991). *Doctors' Stories: The Narrative Structure of Medical* Knowledge: Princeton University Press.

Jurecic, A. (2011). *Empathy and the Critic*. College English, 74, 10-27.

Keen, S. (2007). *Empathy and the novel*. New York: Oxford University Press. https://doi.org/10.1093/acprof:oso/9780195175769.001.0001

Keen, S. (2013). Narrative Empathy. In P. Hühn, J. Pier, W. Schmid, & J. Schönert (Eds.), *The Living Handbook of Narratology*. Hamburg: Hamburg University Press.

Lancaster, T., Hart, R., & Gardner, S. (2002). Literature and medicine: evaluating a special study module using the nominal group technique. *Medical Education, 36*, 1071-1076. https://doi.org/10.1046/j.1365-2923.2002.01325.x

Mai, A.-M., & Simonsen, P. (2017). *Syg litteratur.* Kbh: Munksgaard.

McDonald, P., Ashton, K., Barratt, R., Doyle, S., Imeson, D., Meir, A., et al. (2015). Clinical realism: A new literary genre and a potential tool for encouraging empathy in medical students Approaches to teaching and learning the Many Meanings of 'Quality' in *Healthcare: Interdisciplinary Perspectives. BMC Medical Education, 15*. https://doi.org/10.1186/s12909-015-0372-8

Mehrabian, A. (1996). Manual for the balanced emotional empathy scale (BEES). *Available from Albert Mehrabian*, 1130.

Miller, E., Balmer, D., Hermann, N., Graham, G., & Charon, R. (2014). Sounding narrative medicine: studying students' professional identity development at Columbia University College of Physicians and Surgeons. *Academic medicine : journal of the Association of American Medical Colleges, 89*, 335-342. https://doi.org/10.1097/ACM.0000000000000098

Monica, E.L.L. (1981). Construct validity of an empathy instrument. *Research in nursing & health, 4*, 389-400. https://doi.org/10.1002/nur.4770040406

Muszkat, M., Yehuda, A.B., Moses, S., & Naparstek, Y. (2010). Teaching empathy through poetry: a clinically based model. *Medical education, 44*, 503-503. https://doi.org/10.1111/j.1365-2923.2010.03673.x

Neumann, M., Edelhäuser, F., Tauschel, D., Fischer, M.R., Wirtz, M., Woopen, C., et al. (2011). Empathy decline and its reasons: a systematic review of studies with medical students and residents. *Academic Medicine, 86*, 996-1009. https://doi.org/10.1097/ACM.0b013e318221e615

Newton, B.W., Barber, L., Clardy, J., Cleveland, E., & O'Sullivan, P. (2008). Is There Hardening of the Heart During Medical School? *Academic Medicine, 83*, 244-249. https://doi.org/10.1097/ACM.0b013e3181637837

Nussbaum, M.C. (1997). *Cultivating Humanity: A Classical Defense of Reform in Liberal Education*: Harvard. https://doi.org/10.2307/j.ctvjghth8

Ousager, J., & Johannessen, H. (2010). Humanities in undergraduate medical education: a literature review. *Academic Medicine, 85*, 988-998. https://doi.org/10.1097/ACM.0b013e3181dd226b

Patterson, A., Sharek, D., Hennessy, M., Phillips, M., & Schofield, S. (2016). Medical humanities: A closer look at learning. *Medical Humanities, 42*, 115-120. https://doi.org/10.1136/medhum-2015-010834

Pennebaker, J.W., Francis, M.E., & Booth, R.J. (2001). *Linguistic inquiry and word count: LIWC 2001*. Mahway: Lawrence Erlbaum Associates, 71, 2001.

Pfeiffer, S., Chen, Y., & Tsai, D. (2016). Progress integrating medical humanities into medical education: a global overview. *Current Opinion in Psychiatry, 29*, 298-301. https://doi.org/10.1097/YCO.0000000000000265

Rasmussen, A.J., & Goyal, R. (2017). What Does it Mean to Listen, and How Can it Be Learned? In B.G.b.M. Humanities (Ed.). *British Medical Journal*: ACI Information Group.

Rosenthal, S., Howard, B., Schlussel, Y.R., Herrigel, D., Smolarz, B.G., Gable, B., et al. (2011). Humanism at heart: Preserving empathy in third-year medical students. *Academic Medicine, 86*, 350-358.https://doi.org/10.1097/ACM.0b013e318209897f

Scells, H., Zuccon, G., Koopman, B., Deacon, A., Azzopardi, L., & Geva, S. (2017). Integrating the framing of clinical questions via PICO into the retrieval of medical literature for systematic reviews. *Proceedings of the 2017 ACM on Conference on Information and Knowledge Management* pp. 2291-2294): ACM.https://doi.org/10.1145/3132847.3133080

Schleifer, R., & Vannatta, J. (2013). *The chief concern of medicine: the integration of the medical humanities and narrative knowledge into medical practices*: University of Michigan Press. https://doi.org/10.3998/mpub.3157169

Shankar, P.R. (2013). Developing and sustaining a medical humanities program at KIST Medical College, Nepal. *Indian journal of medical ethics, 10*, 51-53.https://doi.org/10.20529/IJME.2013.012

Shapiro, J., Duke, A., Boker, J., & Ahearn, C.S. (2005). Just a spoonful of humanities makes the medicine go down: introducing literature into a family medicine clerkship. *Medical Education, 39*, 605-612. https://doi.org/10.1111/j.1365-2929.2005.02178.x

Shapiro, J., Morrison, E., & Boker, J. (2004). Teaching Empathy to First Year Medical Students: Evaluation of an Elective Literature and Medicine Course. *Education for Health: Change in Learning & Practice, 17*, 73-84. https://doi.org/10.1080/13576280310001656196

Shapiro, J., Ortiz, D., Ree, Y.Y., & Sarwar, M. (2016). Medical students' creative projects on a third year pediatrics clerkship: a qualitative analysis of patient-centeredness and emotional connection. *BMC Med Educ, 16*, 93. https://doi.org/10.1186/s12909-016-0614-4

Shapiro, J., Rucker, L., Boker, J., & Lie, D. (2006). Point-of-view writing: A method for increasing medical students' empathy, identification and expression of emotion, and insight. *Education for Health: Change in Learning & Practice, 19*, 96-105. https://doi.org/10.1080/13576280500534776

Tsai, S.L., & Ho, M.J. (2012). Can narrative medicine training improve OSCE performance? *Medical Education, 46*, 1112-1113. https://doi.org/10.1111/medu.12029

Wieżel, I., Horodeńska, M., Domańska-Glonek, E., & Torres, K. (2017). Is There a Need for Narrative Medicine in Medical Students' Education? A Literature Review. *Medical Science Educators, 27*, 559-565. https://doi.org/10.1007/s40670-017-0426-0

Zahavi, D. (2014). Empathy and Other-Directed Intentionality. *Topoi, 33*, 129-142. https://doi.org/10.1007/s11245-013-9197-4

Zimmermann, M. (2013). Integrating medical humanities into a pharmaceutical care seminar on dementia. *American journal of pharmaceutical education, 77*, 16. https://doi.org/10.5688/ajpe77116

Notes

1 The present organization of the mandatory course in Denmark is different from the typical, required course at Co-lumbia. Our goal is to develop our course towards the model at Columbia which offers 12-13 medical seminars to choose among, each with a participation limit of 12. Here one can choose seminars like "Poetry: Close Readings and Craft", "The Medical Student as Writer", "The Philosophy of Death", "An Exploration of Dance and the Spectrum of Physical Narrative", "Observation and Uncertainty in Art and Medicine", and "Photography and Visual Storytelling", some of them taught at the Medical School and some taught at Museum of Modern Art or Metropolitan Museum of Art.

2 MD and PhD Mohammadreza Hojat, has developed instruments to measure empathy in the context of health profes-sional education and health care (Hojat, 2016). *The Jefferson Scale of Empathy* is a quantitative measurement of physicians' empathy with patients relying on a questionnaire including questions as "I believe that empathy is an important therapeutic factor in medical treatment", which is answered on a 7-point scale from "strongly disagree" to "strongly agree". For a discussion of if and how empathy is correlated to literature, see Suzanne Keen *Empathy and the Novel* (2007) and Ann Jurecic "Empathy and the Critic" (2011).

3 Counter to this position, philosopher Dan Zahavi has argued in "Empathy and Other-Directed Intentionality" (Zahavi, 2014) that empathy in the phenomenological tradition is rather understood as a mental resource used by the subject in order to understand how other subjects feel, think and react. Furthermore, this leads to understanding empathy as a spontaneous reaction to others which is inborn and cannot be learned or unlearned.

4 This was provided by our University's Research Support Unit "Videncentret" (http://videncentret.dk/for-researchers/tools/).

5 See e.g. Cooper & Tauber; Kuper in (Ousager & Johannessen, 2010)

Originalartikel

"I'm sure that there is something healing in the writing process"

Creative Writing Workshops for People with a Cancer Disease

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People with cancer often experience side-effects, such as; anxiety, altered body image, and decreased quality of life. Rehabilitation programs are established to support people with cancer in relation to their physical, psychological, and social challenges. The aim of our *study was to assess how people with cancer needing rehabilitation, experienced a creative writing workshop (the intervention); especially, in relation to increasing their well-being and boosting their communicative skills. The intervention drew on narrative medicine, including its methods of creative writing and close reading. The workshops were held as residential workshops. Two writers of fiction with expertise in teaching led the teaching in groups of 10 participants each. The assessment is based on an ethnographic fieldwork at the creative writing workshops, including participant-observation, and interviews with 23 of the 39 participants after the workshops. The findings are presented in two themes; Writing and reading aloud and Community. After a discussion of these findings, we conclude that creative writing workshops for people who are being treated for cancer and are in need of rehabilitation may have a positive impact on their well-being and communicative skills, but more research is needed about the effects of creative writing on the rehabilitation of people with cancer.*

Introduction

Cancer diseases are a worldwide burden today, raising a lot of challenges in health care which are aggravated by an aging population. People living with cancer often experience short-term and long-term side-effects; such as, anxiety, depression, pain, altered body image, and decreased quality of life. Rehabilitation programs are established to support people with cancer in strengthening their experience of well-being and quality of life in relation to physical, psychological, and/or social challenges. In recent years, various kinds of methods for writing texts and reading literature have gained interest as a means of supporting rehabilitation (e.g., well-being and quality of life). Furthermore, some studies have examined the therapeutic effects and other benefits of such creative activities (Pennebaker 2004; Gripsrud et al. 2016; Hellum et al. 2017). However, hypotheses of relevant health outcome(s) and assessment of these effects are still in need of theoretical investigation and reliable, empirical evidence (Stuckey & Nobel, 2010; Fioretti et al. 2016). In this article we investigate how people with a cancer disease who are in need of rehabilitation, experience a creative writing workshop in a Danish context, especially in relation to increasing their well-being and boosting their communicative skills.

Background

The intervention in the study draws on the relatively new, international field of narrative medicine. Narrative medicine is most prominently developed by Rita Charon, professor of internal medicine and PhD in English literature (Charon, 2006), and her colleagues at Columbia University in New York. Since 2000, the field has developed and expanded from Columbia University and throughout the world. Additionally, the interpretation of what defines this new, interdisciplinary field varies. Unifying for all approaches to narrative medicine, is the conviction that clinical skills to recognize, understand and witness the stories patients tell can be cultivated through methodological rigorous work with art, and especially literature. A few new studies have investigated how the methods of narrative medicine can be applied directly to patients and not only their caregivers (Fioretti et al., 2016).

According to Nellie Hermann, writer of fiction and teacher of narrative medicine at Columbia University, the effects of creative writing are threefold; 1) by moving what is internal to the external, one creates an alleviating shape for past experiences and more space for new experiences, 2) by writing about experiences, one also creates objects that can be examined by oneself from different perspectives, and 3) by reading the written texts aloud one allows others to share their experiences. Hermann argues further that when reading spontaneously written texts aloud to others, these listeners are invited to see (and perhaps share) things about the writer's text that may not have been evident before the act of writing (Hermann, 2017:215). Creative writing is nearly always combined with a close reading of a text. By close reading, Charon means paying attention to the textual form; e.g., narrative voice, representation of space and time, and use of metaphor (Charon 2017). The normal procedure during a teaching session at Columbia University is that a fictional text is read closely, followed by a writing session, and finally these spontaneously created narratives are read aloud and commented on. So far, this kind of writing and reading aloud has only been practiced successfully with medical and health care students to improve their clinicals skills of attentive listening, empathy and trustful relations (ibid. 2017). The present intervention is moving into new territory when applying creative writing and reading aloud practices for people with cancer in need of rehabilitation.

Independent to the expansion of narrative medicine, others have been practicing writing and reading aloud with patients in order to improve health outcomes, such as the quality of life. Writer of fiction Gillie Bolton (2011), has developed a framework for how to develop and implement creative writing with various patient groups in England. For professor of English literature at the University of Liverpool Josie Billington, enlargement of life horizon has been the most important use of literature, when she practiced *"shared reading"* with patients (2016). Moreover, American psychologist James W. Pennebaker, who is considered to be the leading researcher on the power of writing for therapeutic purposes, argues that when people with traumatic experiences articulate their feelings and thoughts in written language, their physical and mental health often improve (Pennebaker 2004). Although the causality between an aesthetic activity and health-related effects seem to be complex and unpredictable, Charon argues that creative writing as discovery, invention, and imagination might help people to find new, healing powers and expand their horizons beyond the restricted realms of illness (Charon, 2016:11). Contrary to expressive writing, creative writing is not in itself intended to be used as a therapeutic intervention, but it can have therapeutic effects.

Additionally, creative writing is explicitly non-expressive; e.g., the participants are *not* instructed to write about their disease and treatment. Instead, the formal aspects of writing; such as, how a room is depicted, how a birthday is rendered, or how an imaginary dialogue unfolds, are supposed to energize the writer. This approach is close to what medical sociologist Arthur Frank calls, *"thinking with stories"*. In his words, *"To think about a story is to reduce it to its content and then analyze that content […] To think with a story is to experience it affecting one's own life and to find in that effect a certain truth of one's own life"* (Frank 1995: 23).

Some studies have been conducted on the health effects of writing and reading. One such study was a meta-study of current research literature considering the connection between art and health (mainly in USA and Europe) and stated that the use of aesthetic activities is associated with statistically significant improvements in physical and psycho-social health; such as, reducing the number of visits to physicians and improving immune system functioning (Stuckey & Nobel, 2010: 259). One limitation of this meta-study is that only a few of the studies assessed the effects of writing and reading.

Pennebaker and Chung have published (2012) a meta-study of reviews of current research literature considering the connections between expressive writing and health, which concluded that expressive writing can among other things; promote sleep, enhance immune function, and reduce alcohol consumption. One Scandinavian study stated that patients with breast cancer who used expressive home writing, may produce a release of cognitive, emotional, and relational tension. Additionally, it may also be effective in reducing these patients' frequency of visits to a physician and have beneficial effects on somatic factors, like their pain symptoms (Gripsrud et al., 2016).

A recent systematic review focused on studies that specifically incorporated narrative medicine (Fioretti et al., 2016) and out of the 10 studies where the term 'narrative medicine' was mentioned in either the title or keywords, none of them applied creative writing with a facilitator like our study does. Almost every study used a different method, varying from drawing to storytelling. In their conclusion, the authors recommend that researchers should find a common methodology and share their procedure of assessing the interventions; which allow the study to be replicated in other contexts and with patients suffering from other diseases. Three of the 10 studies investigated health effects on cancer patients; one of these, was a randomized control trial with 234 participants (Cepeda et al., 2008) and included a 20-minute home narrative session intervention, once a week for three weeks. The overall results were neutral; the patients who participated in the narrative writing intervention had the same pain intensity and sense of well-being (Likert scale), as the patients in the two control groups. Nonetheless, a few patients with high emotional disclosure in their narratives reported a decrease in their level of pain and an increase in their well-being when compared to a larger group of patients who had no emotional disclosure in their narratives. This result suggests that writing is not for everyone, and that the intervention's health effect may be dependent on how the writing is both conducted and measured.

The aim

The purpose of our study was to assess how participants in need of cancer rehabilitation experienced a creative writing workshop, especially in relation to increasing their well-being and boosting their communication skills. Based on the literature, the assumption was that creative writing workshops could support the participants to find a new creative form and new narrative structures on their thoughts and feelings about themselves and the world; and by facilitating the externalization of their inner life in imaginary texts and by sharing of these creative fragments, the participants might activate a reservoir of healing.

The Intervention

The intervention was designed as a creative writing workshop for people who were being treated for a cancer disease and needed rehabilitation. Theoretically grounded in the field of narrative medicine, the intervention focused mainly on creative writing and reading aloud. The intervention took place at The Danish Knowledge Centre for Rehabilitation and Palliative Care (REHPA) which is situated in the town of Nyborg in the Region of Southern Denmark. REHPA primarily provides residential courses and workshops that address a combination of short and long terms side-effects and challenges; including physical, mental, social, and existential problems for people who have been or are treated for a cancer disease (Zwisler et al., 2017). The content and structure of the intervention in our study was developed based on previous experiences from a creative writing workshop for people from a local rehabilitation center in Odense, Denmark, with a chronic alcohol abuse problem (Hellum et al., 2017a; 2017b). The model for the creative writing workshops was developed in collaboration with REHPA, two writers of fiction, literary scholars and teachers of narrative medicine at University of Southern Denmark. The creative writing workshops were designed as two residential workshops and held twice. *Workshop I* in 2016-17 consisted of a two-days writing sessions and a one-day writing session held one month later; whereas, *Workshop II* in 2017-18 consisted of a two-days writing sessions followed by two-days of writing sessions one month later. Two writers of fiction who were also experienced at teaching creative writing to people with severe health problems, led the teaching and the individual work in two groups with each group consisting of approximately 10 participants.

The aim of the intervention should be attained through sessions with different kinds of writing and reading activities; including, creative writing in small groups, non-stop writing over a given theme, reading aloud one's own texts, listening to texts read aloud by others, comments, discussions and reflections on other's texts, followed by writing exercises at home. Only meals, breaks and socializing in the evenings were scheduled. It was the teachers' responsibility to plan the content and the structure of the two writing workshops which were held twice a day (morning and afternoon) and lasted about 2-3 hours each; and included two 20-minutes breaks at a fixed time and a 45-minute break in the afternoon where the participants could go for a walk, do some fitness training or relax in their rooms.

The overall idea of the workshop was that the participants should work with their creativity through writing incorporating different genres of writing and reading aloud to boost their skills in nuanced communication and ability to cope with their illness. Therefore, it was requested that the participants did not write about their cancer disease. The participants experienced this as both surprising and for most of them, as a relief. On the first day of the workshop, one of the teachers said:

> *"We all know that you have been seriously ill, perhaps you have been experiencing pain, fatigue and anxiety. You probably worry about your family and they worry about you. This is not surprising. We know it, but you can't make a story out of this. If you are writing: 'I'm so unhappy', it is of course very important for you. However, such a sentence doesn't create a text in itself. So, we are not going to write about your cancer experiences. Instead, we are going to write about lots of other things; for instance, the kitchen from your childhood, when you were in love for the first time and many other things. You are going to learn about how to write and in such a process the theme is not important"* (Hansen's fieldnote from the creative writing workshop in November 2016).

The participants

The participants recruited for this study had all been treated for a cancer disease. All participants completed a referment form, including "The Dallund Scale" developed after the Distress Thermometer (Donovan et al., 2014; Kristensen, 2005). This scale measures people's self-evaluated rehabilitation needs. It consists of questions about the participants own goals in relation to their life with a cancer disease. The participants needed to have been referred to the workshop from either the hospital or their general practitioner. The health professional team-leader went through the all the applications to assess if the relevant criteria was fulfilled, and the participants were able to speak, write and understand Danish. Moreover, the participants should be able to participate actively in the workshop; including writing, reading aloud their own texts and take part in the group discussions. There was a maximum of 20 participants per workshop. Participants in the workshops came from different parts of Denmark, some from smaller towns, some from bigger cities and some from the countryside. In *Workshop I*, 17 women and two men participated in the first workshop and 14 (one man and 13 women) in the follow-up workshop. As it was winter, some were sick with the flu, while others were unable to reach the center due to snow and poor road conditions. The oldest participant was 84, the youngest was 46, and 55 was the average age. In *Workshop II*, 16 women and four men participated in the first workshop and 15 (12 women and three men) in the follow-up workshop. A few of the participants' cancer had metastasized, and one participant needed to have plastic surgery, therefore, they were not able to participate in the follow-up session. The oldest participant was 71, the youngest was 21, and 54 was the average age. At both workshops, the participants were divided into two fixed groups with the same writer of fiction as their teacher. The team-leader from REHPA was available during the day and present at lunch. In the evenings and at night, a health care professional was responsible for the social gatherings and supported the participants if they had any needs.

The assessment

The participants' assessments of their experience were part of the general assessment of the creative writing workshops. This article reports on the participants' assessments and was conducted as an ethnographic fieldwork (Zwisler et al., 2017, Hansen et al. 2018). The fieldwork included participant-observation and ethnographic interviews with 23 participants, approximately one month after the end of the intervention. Based on our previous research experiences, we decided that interviewing approximately 10 participants from each workshop would be sufficient and as it turned out that number of interviews was very easily attained.

Participant-observation took place from the beginning to the end of the creative writing workshops. At *Workshop I*, Hansen followed the teaching in one group with one writer of fiction, and at *Workshop II*, Hansen changed and followed the other writer of fiction. She did participant-observation during the creative writing sessions, the breaks, meals, and social gatherings in the evenings. During participant-observation, the field notes were written mostly as; scratch notes, key words, and memos. After the writing workshops, the fieldnotes were read and expanded into a coherent text by Hansen.

The participants could decide themselves if they wanted to be interviewed or not. From *Workshop I*, one man and 10 women were interviewed, and from *Workshop II*, four men and eight women were interviewed. The ethnographic interviews were performed approximately three months after the workshops. Hansen did the interviews with the participants from *Workshop I*, and Laursen interviewed the participants from *Workshop II*. All the interviews, except two, took place in the participants' homes. Of the remaining two participants not interviewed at home, one participant was interviewed over skype by Hansen and the other was interviewed over phone by Laursen. Each interview lasted a little more than one hour and were digitally recorded and transcribed verbatim by the respective interviewers. An interview guide was used to support the interviewers and participants in keeping on track.

Ethics

The study received an umbrella approval from the University of Southern Denmark and the Danish Data Protection Agency (journal number for *Workshop I;* 16/95.500 and for *Workshop II*; 18/10271). Participants gave written informed consent. At *Workshop I*, there was one participant who did not want to be observed during the writing session; therefore, she was placed in the non-observation group. For the purpose of anonymity, all the names of the participants included in this article are fictive.

The analytic process

The analysis was based on qualitative description (QD) (Neergaard et al. 2009). QD is based on an enriched, straight forward description of an experience or an event. The aim of QD is to describe the participants' experiences, thoughts and felings; as close to the participants own language as possible. This analytic strategy means that QD only involves low-inference interpretation. Initially, our empirical material (fieldnotes and transcribed interviews) was read thoroughly several times by Hansen and Laursen. The purpose of this reading was to identify and code emerging themes about how the participants experienced the writing workshops, guided by; the aim of the study, the interview guide, the literature about narrative medicine, and the workshop activities. The transcripts and the fieldnotes were analyzed to find participants' words, sentences, and utterances that addressed their experiences, thoughts, and feelings about the content and structure of the workshops; including, any reflections they had on their well-being, communication skills (orally/written), or if they expressed experiencing any non-pleasant or harmful experiences.

Findings

From an overall perspective, the empirical material showed that nearly all the participants were positive when they talked about the content and the structure of the creative writing workshop; which is what was also reflected in the written evaluation questionnaires REHPA received from the participants (Zwisler et al. 2017). It is important to state that people with cancer participating in some form or another of these residential rehabilitation workshops at REHPA, most often articulate their appreciation for these courses. However, during the workshops and the interviews, a few participants expressed some concerns they had about the writing workshops. In the following paragraphs, our findings are presented in two themes, namely; *Writing and reading aloud* and *Community*.

Writing and reading aloud

Throughout the workshops, the participants were engaged in writing and reading their texts aloud for each other. Many participants repeatedly stated in the beginning and during the workshops that they needed tools to be able to write and structure their thoughts, experiences, and memories:

> *"I need structure. My writing quickly becomes a mess"* (fieldnote from the introduction session, workshop II, Jane).

> *"I hope to get some writing tools, so I can be better at writing and finish my text"* (fieldnote from the introduction session, workshop II, Karen).

> *"I thought it was fantastic. I have never been through such a good and important teaching […] it was so practical and so useful"* (fieldnote during a coffee break, workshop II, Doris).

> *"I think that the teacher is talking too much, and sometimes it has nothing to do with the writing exercise. I came here to write and to get some tools"* (fieldnote from a break, Jonna, workshop II).

The usefulness of the writing tools was also brought up during the interviews where some participants stated that with these tools at hand, they felt more confident about writing, because they had learned how to avoid 'dead metaphors' and 'poor adjectives' and how to structure their text in a narrative way:

> *The teacher gave us very specific tools; how to do this and that, and I could simply write them down and use them when I got home. She told me I could do this, because I sometimes doubted my ability to write. With her critical eyes she also showed me what was working well in my texts. It was also fun to hear the others reading aloud, and with the feedback we received, it became hugely meaningful – and the teacher went deep into our texts to help us improve them. That was so useful* (Linda, workshop I).
>
> *For me, it was so good that we wrote so much, because I tend to have writer's block. It was fantastic to discover that one could use all these tools to overcome writer's block and get beyond it* (Minna, workshop 1).
>
> *At the beginning of the workshop I had writer's block and was scared, because I've never really wrote anything before. And the teacher told us that writing was so fantastic. I felt I was forced to participate in the workshop – and I thought that there should have been someone from REHPA* (Jackie, workshop 1).

Several participants noted that the writing tools also helped them to think differently about their life and illness:

> *The teacher encouraged me to write (and think) in third-person, and this technique helped me a lot, both when I write and when I am out walking. For me, thinking in third-person is a way to distance myself from the illness* (Nora, workshop I).
>
> *The writing really helps me. I think I am more optimistic of my life situation now. The homework writing was so difficult. But – then I got feedback from the teacher and the other participants. That was very helpful and gave me faith that life could continue* (Peter, workshop II).
>
> *The creative writing workshop was important, because you get something good out of it – a loving and hugging kick – and someone telling you 'I believe in you'. I am sure that there is something healing in the writing process* (Doris, workshop II).

> *As the teacher told us, I have now started thinking in third-person as a useful technique. So, sometimes when I am out for a walk, I have thoughts in third-person and this creates a distance to my illness; it feels so cool. And I don't think I would have figured this out by myself* (Nora, workshop I).

When the participants had finished a writing exercise, they continued to read their texts aloud to the others in the group. During the act of reading aloud, the only sound one could hear came from the reader. The other participants had turned their gaze towards the reader, sometimes they nodded, perhaps they dried a tear away, or came with encouraging words, such as; '*You are so good at describing your childhood room*' (fieldnote, workshop I). Most often the teacher started commenting on the text just read aloud, for example saying:

> *Thank you, Vera. You described the situation in such a way that I felt I was there. I could recognize the feelings you were describing. In the next writing exercise, I suggest that you pay a little more attention to dead metaphors. Do you remember (talking to the whole group) that we talked about dead metaphors yesterday? (some of the participants nodded their heads). Let's now hear what you [the other participants] have to say about Vera's text* (fieldnote, workshop II).

During the interviews, the participants often reflected on the process of reading aloud, saying:

> *I experienced it as being very positive to hear the others read aloud [..]. It is incredibly inspiring to hear the different writing styles of the others* (fieldnote, workshop I).

> *It was wildly exciting to hear the others read aloud. I would have felt cheated or vexed if they hadn't read aloud. To read one's own text aloud – one's first text – but it was the same for everyone – it was transgressive. The teacher helped us to get rid of our feelings about exposing ourselves* (fieldnote, workshop II).

One to two participants found that reading aloud in the groups made the workshops very long and a few participants expressed during the interviews that they were not sure if the workshops could be related to their rehabilitation process. For instance, Chris said:

> *It has been a nice workshop, but I can't really see that it has any relevance to my disease* (workshop II).

During the interviews, some of the participants expressed that they had continued writing at home:

> *It is so important to find words for the issues that are important to me. I write to feel better* (Mona, workshop II).

> *I write one to two hours each time. I discover new things, I see new things and I can get a hold on something that has been on my mind for a long time. It makes me glad, and it helps rearrange something inside me* (Linda, workshop I).

However, for many of the participants it was difficult to find time or energy to write at home. They expressed a wish to write and hoped that they could manage this in the future. Some said:

> *I have come the conclusion that, although I have not written anything at home, the workshop has somehow helped me, because I have had a lot of ideas about what I want to write about* (Minna, workshop I).

> *I wrote a speech for my sister, and I used the tools we learned at the writing workshop. I posted my speech on Facebook, and I received some comments. I used the techniques I learned from the teacher. I was very happy* (Tanja, workshop I).

Although only some of the participants continued using the writing tools after the workshops, most of the participants experienced that they could use the creative writing workshops in one way or another in the daily life, and for some – but not all – it also helped them to cope with their illness.

Community

The participants highlighted how important it had been that the health professionals at REHPA and the teachers had created a safe space for them where they could read their short texts aloud, could share experiences with each other, and could feel comfortable knowing that the other participants knew what it was like to have a cancer disease. Many of the participants emphasized that attending this residential rehabilitation workshop was something special, and that they had been looking forward to having a night's rest 'away from home'. The participants had different reasons for this; some looked forward to the luxury and aesthetics of staying at a hotel (*Workshop I*), while others mentioned the cozy rooms at REHPA (*Workshop II*). Many pointed out that they felt relaxed, understood and taken care of during the writing workshops. Hansen wrote in her fieldnotes:

> *Tears frequently came to the eyes of the participants when they were reading aloud, and very often a participant sitting next to the reader put a hand on the reader's shoulder. Slowly and silently their hand moved a little bit up and a little bit down, then a little bit from one side to the other side until the reading had stopped* (fieldnote, workshop I).

For some of the participants it was overwhelming how quickly they felt a kind of community with the others because of the act of reading aloud their own texts. For example, during a coffee break two participants embraced each other, and one of them said:

> *It is really a good thing that we are going to read aloud. We get to know each other quickly* (fieldnote from small talk between two participants during the evening coffee break, workshop II).

> *You get some sense of unity or community or something like that […]. You're in the same boat […] when you are together with others that have had cancer too. You don't have to talk a lot to explain yourself* (interview, Doris, workshop II).

> *It is very liberating to be with the other participants – because you don't have to explain so much – and if you have a chemo brain or whatever else you are experiencing – sore feet, for instance – it is okay. The workshop gave us a welcome respite* (interview, Linda, workshop I).

> *It is a good thing to be away from everything – to meet someone like me – to be taken seriously* (fieldnote from a writing session, workshop I).

> *When you are at home, you have so many thoughts. It was fantastic to get away – to meet others like yourself – and listen to their stories about how they manage*

> *their daily life – how they turn their thoughts away from their illness and listen to their input* (interview, Nora, workshop I).

> *To be together is important – and in small groups – it is incredibly life-affirming to be with the others, you get away from the illness – and then you get out and feel free in a new way* (interview, Peter, workshop II).

Most of the interviewed participants expressed that the community of being with others with the same illness as themselves was valuable and enhanced the benefits of the writing workshop; for example, it allowed them to express thoughts about their illness without having to further explain it. However, a few were indifferent that they shared a common illness:

> *The social relations didn't mean very much to me – perhaps for other people. In my family we have a huge network. I came there [to the workshop] because of the content – to get some writing tools* (interview, Martin, workshop I).

A few of the participants expressed during the interviews, that in the beginning of the workshop it had been challenging to have an observer in the group, but as soon as they began writing and reading aloud, they forgot about the observer.

Discussion

Our study showed that most of the participants in this intervention (*Workshop I and Workshop II*) expressed that the creative writing workshops gave them a positive outcome. For many of the participants, the workshops seemed to have supported them in; coping with their cancer disease, increasing their self-confidence, and putting their life in the foreground by moving their disease to the background. This is close to what Charon argued, namely, that creative writing can have a therapeutic effect (Charon 2006; Charon et al. 2017). For some of the participants the workshops had strengthened their writing skills and/or opened a new means of communicating and to be happy. Furthermore, the findings demonstrate that creating a sense of community is an integral part of the workshops, for the participants to be able to show each other their writings, read aloud and express thoughts and feelings that typically are difficult to share with others. It is important to be in a 'safe space' in close relation to health professionals, other participants with a cancer disease, and experienced, empathetic teachers.

These findings are in line with the findings from another study based on creative writing workshops in a Danish healthcare system and disease context (Hellum et al. 2017a, 2017b), and these studies have both explicitly applied the method of creative writing as it is practiced in narrative medicine. This similar study was organized as six weekly sessions for patients with an alcohol abuse problem. The study found that the patients expressed increased self-confidence, zest for life, and the ability to better appreciate the nuances of life after participating in the creative writing workshop. Furthermore, this study has been replicated with equally positive results (Tarp et al. 2019); yet the sample size is still very small and there has been no control group included.

sample size is still very small and there has been no control group included.

We argue that it seems like many of the participants were able to move internal worries to external and sensuous texts; thereby creating more space for new experiences of life and allowing themselves to examine their feelings, experiences, etc. from different perspectives (Hermann, 2017:215). Moreover, our findings are aligned with the practice of narrative medicine in the sense that reading aloud a written text is an important element, as this allows the participants to share their personal experiences with others. Sharing something personal which someone has written with 'strangers' makes one feel more vulnerable and better understood than when telling the same story informally. Hermann states that the vulnerability one might feel when sharing an intimate story, puts one at each other's mercy; and the responses one receives can be powerful in building one's trust (ibid.:217). Additionally, the findings also demonstrated that the facilitator's critical and encouraging remarks to the participants' texts seems to have enhanced the participants' potential for self-reflection and meaning-making.

Some of our findings showed how a few of the participants had concerns about the setup of the workshops. These concerns have already been used to improve the design of the forthcoming creative writing interventions planed for the fall of 2019 and spring of 2020.

Conclusion

We have in this article argued that creative writing workshops, modelled by the method of narrative medicine, for people treated for a cancer disease and in need of rehabilitation, may have a positive impact on their life. The experiences of the participants were mostly positive, in relation to having learned how to use different kinds of writing tools and how a narrative structuring of their thoughts and feelings could support them in coping with their illness story. Furthermore, we can conclude that a safe and stimulating space is necessary to create a sound, trustful, and enjoyable community between the participants. As we have shown, many of the participants stated that the writing workshop helped them to improve their oral and/or written communicative skills in daily life. Yet, there is not sufficient evidence as to how the participants practice this coping potential and these new skills for their own benefit and/or in interaction with family, friends, colleagues and health care professionals. Therefore, we want to point out that more research on the effects of creative writing workshops is needed to address whether creative interventions with words and stories can be complementary to other interventions, and if so, how they can complement evidence-based rehabilitative outcomes.

References

Billington, J. (2016). *Is Literature Healthy?* Oxford University Press.

Bolton, G. (2011). *Write Yourself. Creative Writing and Personal Development*. Jessica Kingsley.

Cepeda, S et al (2008). Emotional Disclosure Through Patient Narrative May Improve Pain and Well-Being: Results of a Randomized Controlled Trial in Patients with Cancer Pain. *Journal of Pain and Symptom Management, vol. 36, no. 6*, 623-631. https://doi.org/10.1016/j.jpainsymman.2007.08.011

Charon, R. (2006). *Narrative Medicine. Honoring the Stories of Illness*. Oxford University Press.

Charon, R et al. (2017). *The Principles and Practice of Narrative Medicine.* Oxford University Press. https://doi.org/10.1093/med/9780199360192.001.0001

Charon, R. (2016). The Shock of Attention. *Enthymema, 16*: 6-17.

DasGupta, S. Charon, R. (2004). Personal illness narratives: using reflective writing to teach empathy. *Acad Med*; 79:351-6. https://doi.org/10.1097/00001888-200404000-00013

Donovan KA et al. (2014). Validation of the Distress Thermometer worldwide: state of the science. *Psycho-Oncology 23 (3)*:241-250. https://doi.org/10.1002/pon.3430

Fioretti, C et al., (2016). Research studies on patients' illness experience using the Narrative Medicine approach: a systematic review. *BMJ Open, vol. 6, issue 7*. https://doi.org/10.1136/bmjopen-2016-011220

Frank, A. (1995) *The wounded storyteller. Body, Illness, and Ethics*. Chicago. The University of Chicago Press. https://doi.org/10.7208/chicago/9780226260037.001.0001

Gejl, T. (2017). Har litteraturen et helende potentiale? In: A. J. Rasmussen (ed.). *Læse, skrive og hele. Perspektiver på narrativ medicin*. (pp. 71-¬-78.) Syddansk Universitetsforlag. [Does literature have a healing potential?/Read, write, and heal. Perspectives on narrative medicine].

Gripsrud, BH et al. 2016. Capturing the experience: Reflections of women with breast cancer engaged in an expressive writing intervention. *Journal of Cancer Nursing, 39(4)*, 51-60. https://doi.org/10.1097/NCC.0000000000000300

Hansen HP, Tjørnhøj-Thomsen T, Johansen C (2011). Rehabilitation interventions for cancer survivors: The influence of context. *Acta Oncologica. 50*: 259-264. https://doi.org/10.3109/0284186X.2010.529460

Hellum R et al., (2017a). Is training in creative writing a feasible treatment adjunct for clients suffering from chronic alcohol use disorder? *Nordic Studies on Alcohol and Drugs, vol. 34(4)*, 299-313.https://doi.org/10.1177/1455072517696507

Hellum, R., & Nielsen, AS. (2017b). Kreativ skrivning som tilbud i alkoholbehandlingen. In: A. J. Rasmussen (ed.). *Læse, skrive og hele. Perspektiver på narrativ medicin* (pp. 57-¬70). Syddansk Universitetsforlag, [Creative writing as a treatment adjunct for people with chronic alcohol dependence/Read, write, and heal. Perspectives on narrative medicine].

Hermann, N. (2017). Creativity. In: R. Charon et al. *The Principles and Practice of Narrative Medicine*. (pp. 211-232). Oxford University Press.

Kristensen, T. (2005) [The Dallund Scale. Visitation of cancer patients to a rehabilitation, Project anno 2004] *Dallundskalaen. Visitation af kræftpatienter til rehabilitering, projekt årgang 2004*. RehabiliteringsCenter Dallund, Søndersø.

Llambías, P. (2017). Der er ingen forskel på at undervise mennesker med kræft og mennesker uden kræfter i skrivekunst. In: A. J. Rasmussen (ed.). *Læse, skrive og hele. Perspektiver på narrativ medicin*. (pp. s. 51-56). Syddansk Universitetsforlag. [There is no difference between teaching people with cancer and people without cancer creative writing/ Read, write, and heal. Perspectives on narrative medicine].

Llambías, P. (2015). *Skrivning for begyndere. Om skønlitterær skrivekunst for begyndere - en personlig refleksion*. Gyldendal. [Writing for beginners: On fiction writing for beginners - a personal reflection].

Neergaard, M.A. Olesen, O., Andersen, R.S., Sondergaard, J. (2009). Qualitative description - the poor cousin of health research? *BMC Medical Research Methodology, 9:52* https://doi.org/10.1186/1471-2288-9-52

Pennebaker, J. 2004. *Writing to Heal. A Guided Journal for Recovering from Trauma and Emotional Upheaval*. New Harbinger Publications.

Pennebaker, JW and Cindy KC. 2012. Expressive Writing, Emotional Upheavals, and Health. In H. Friedman and R. Silver (eds.) *Handbook of Health Psychology*. Oxford University Press, 263-284.

Stuckey, H, & Nobel, J. (2010). The connection between art, healing, and public health: A review of current literature. *American Journal of Public Health 100, 2*, 254-¬-263. https://doi.org/10.2105/AJPH.2008.156497

Tarp, K, Hellum, R, Rasmussen, AJ, Nielsen, AS. 2019. Can creative writing as an add-on to treatment for alcohol use disorder support rehabilitation? *Alcoholism Treatment Quarterly* https://doi.org/10.1080/07347324.2019.1636736

Zwisler, A.D. et al. 2017. *Skriveværksted. Skrivning som innovativ indsats i rehabilitering og palliation*. REHPA, notat nr. 6, September 2017.

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Originalartikel

Why do we read illness stories?

Paul Kalanithi's When Breath Becomes Air (2016) read in the light of Rita Felski

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Why do we read pathographies and why have they become so popular? These are the key questions in our paper. In answering these, we will introduce and discuss Rita Felski's The Uses of Literature (2008) in connection to the American bestseller and Pulitzer prize finalist pathography When Breath Becomes Air (2016) by Paul Kalanithi.

We chose Kalanithi's book because we consider it in many ways typical of the pathographical genre with its first-person narrator, the frequent expression of shock, its reflections on meaning of the illness and the focus on daily life. Rita Felski's The uses of literature reflects by means of the four concepts knowledge, recognition, shock and enchantment upon what makes us want to read a certain book or genre. However, when working with Kalanithi´s novel we soon found that Felski´s four modes were not only meaning-making for enlightening the question on why we as readers turn to this book. We soon also found that recognition, enchantment, knowledge and shock were concepts that were relevant used in connection with Kalanithi´s own experience of becoming ill and being a patient. The *concepts, therefore, seem most useful for reflections on both the reader's response and the author drives of the pathography genre.*

Introduction

Autobiographical or biographical illness stories (pathographies) are experiencing increasing popularity for reasons that are not obvious. Narrative theory rests on an acknowledged post-modern fact that is important for human beings to tell their stories, not least those involving illness: "*We make as well as tell stories of our lives and this is of fundamental importance in the clinical world*" (Mattingly 1994: 811). The increased public interest in pathographies may be due to several reasons. One is the general interest in contemporary autobiographical novelists like Karl-Ove Knausgård, Claus Beck Nielsen and Siri Hustvedt, to mention only a few. This hybrid genre resting on the verge of fiction and biography somehow meets the extreme with pathographies rendering people in intimate and existential threshold situations concerning health and wellbeing. Another reason for the popularity of the pathography genre is the growing interest in and openness toward health issues in media and popular culture. Due to the digital revolution around 1995 medical information and knowledge were easily spread, and on-line communities connected to specific diseases were established (Tjora & Sandaunet 2010:37). With the development from Web 1.0 to Web 2.0, the internet became a place for interaction rather than information (ibid). A growing number of people were given the possibility to publish online and soon online health diaries or blogs, as they were named in 1997, flourished on the world wide web (Du & Wagner 2006: 790). The presence of illness blogs might have triggered a latent interest in personal illness stories also published as analogous books. Other reasons might be the stirring of feelings and possible empathy in the readers, the need for readers to gain access to the hope which is often rendered (Ezzy 2000), an enhanced emphasis on the importance of narratives as meaning-making material (Wiltshire 2000) and a growing sense of the inadequacy of medicine to treat the whole human being.

In 2016, this novel sold a million copies and was placed second among Amazon's best sellers, after "Harry Potter and the Cursed Child" (Gamerman 2016). It has since been translated and published in more than 30 languages, according to an article in "Medscape" from 2016. This book is in many respects typical of the pathographical genre with its first-person narrator, its expression of shock, its reflections on the meaning of the illness and its focus on daily life. At the same time, we acknowledge that Kalanithi's story in some respects differs from the "ordinary" pathography. One pivotal difference is that he was a medical doctor and thus had privileged information about his medical condition. Another is that he had an MA in English literature in addition to his medical degree, which is seen in his manner of writing. The main reason why we chose to study Kalanithi´s book, though, was due to it being such a worldwide bestseller obviously answering some of the claims of the readers to the pathography genre. Another important reason was because of the literary qualities of the text.

The reasons for reading pathographies and the popularity of the genre are the focus of this article. For our theoretical approach, we have chosen Rita Felski's notable work *The Uses of Literature* (2008) in which she summarizes why we choose to read fiction, limiting the answer to four objectives, namely recognition, enchantment, knowledge and shock. Together, Felski´s four concepts offer a pragmatic approach to why readers read. The hermeneutics of suspicion and the literary theorists' emphasis on otherness are replaced by a more general understanding of what we experience upon reading a work of fiction or watching a film. Felski´s many examples are not only canonical, elitists works of art but also popular fictions and films. By taking a bestseller like Kalanithi´s as our example, we use the methodology on a text representing the same popular corpus as Felski likes to highlight. We chose Kalanithi's book because we consider it in many ways typical of the pathographical genre with its first-person narrator, the frequent expression of shock, its reflections on meaning of the illness and the focus on daily life. Felski's four concepts knowledge, recognition, shock and enchantment help bring the methodological tools to reflect upon what makes us want to read a certain book or genre. However, when working with Kalanithi´s novel we soon found that Felski´s four modes were not only meaning-making for enlightening the question on why we as readers turn to this book. We soon also found that recognition, enchantment, knowledge and shock were concepts that were relevant used in connection with Kalanithi´s own experience of becoming ill and being a patient. The concepts, therefore, seem most useful for reflections on both the reader's response and the author drives of the pathography genre.

We will introduce and discuss these four modes proposed by Felski in connection with the American bestseller and Pulitzer Prize finalist, the pathography *When Breath Becomes Air* (2016) by Paul Kalanithi.

However, when working with Kalanithi´s novel, we soon found that Felski´s four modes did not only make meaning as to why we as readers turn to this book. We also found that shock, recognition, knowledge and enchantment were relevant concepts to Kalanithi´s own experience of becoming ill and being a patient. We would like the reader to pay particular attention to the use of Felski´s concepts on these two levels; one intended by Felski herself, and one added by us as an interpretative tool.

An American bestselling pathography

Paul Kalanithi's widow, Lucy Kalanithi, was asked in an interview with *The Guardian* whether the book's success was expected:

> *"It's exceeded our wildest expectations. A month or so before it was published it was getting some critical acclaim but the big question was whether people would actually want to read a book about dying written by a man who had recently died. We weren't sure. But it turns out they do. I think it is because the book is about living as well as dying. And although it is about what happened to Paul it is also about a universal experience – and it is so beautifully expressed."*

Pathographies understood as personal accounts of illness are a new genre, even though stories of personal illness have existed at least since the 16th century (Wiltshire 2000: 411). If we include doctors narrating about patients, however, the genre goes as far back as antiquity (van der Horst 2013). Modern pathographies, meaning biographical or autobiographical texts rendering an illness experience, grew as a genre in the USA in the 1950s (Hawkins 1999), in the UK from the late 1970s (Aronsen 2000: 1600) and in the Nordic countries from the late 1960s (Bernhardsson 2010, Henriksen 2014: 115). In line with the growth of the pathography genre during the last fifty years, the texts have become more diverse, including first-person autobiographical accounts, third-person biographical rendering of illness, and documentary texts as well as fiction. There seems to be a trend for modern pathographies to be less accepting and more often "*[a] critical patient narrative*" (Wiltshire 2000: 412), formulating protests of being transformed into a body rather than being a person within the biomedical system.

When Breath Becomes Air is, however, not a critical pathography, either in its view on health care or in the feelings stirred in the author-patient himself. The biography about illness and dying by the late American neurosurgeon Paul Kalanithi (1977-2016) is marked by the success its author experienced as a doctor and the brave manner in which he faced his illness. Parts of the book were published as essays at high-profile media outlets like *The New York Times* while Kalanithi was still alive, but the whole book was published posthumously ten months after his death. The book consists of a prologue and two parts. It is framed by a foreword by the celebrated Indian-American physician-author Abraham Verghese, and an epilogue written by the author's wife Lucy Kalanithi. Both the introduction and the epilogue stress the "human touch" of Kalanithi´s biography and adds crucial information about him, both from a professional and a private perspective. More pragmatically, the introduction written by a medical celebrity like Verghese gives the book credibility and grandeur that makes it stand out from the majority of other pathographies. The prologue opens with the 36-year-old author flipping through his own CT scans, confirming his suspicions that he is suffering from incurable cancer.

Part one, "In Perfect Health I Begin", is a highly curated selection of the author's life story up to falling ill. Apart from sketched portraits of his Indian parents, this is the author's story of how he first became an English literary scholar, then a doctor, then a neurosurgeon. He cites his motivation for his educational choices as a search for answers to the question: What makes human life meaningful? He soon develops a fascination for the human brain, the biological organ that enables meaning. Finally, he realizes that questions about "life, death and meaning" more often arise in a medical context, and particularly connected to brain damage. In part two, "Cease Not till Death", Kalanithi expresses great disappointment that he has to stop working just as he is about to graduate as a neurosurgeon and was to be appointed an attending professor. His identity as a person is strongly tied to his professional identity; who is he, if not a neurosurgeon? The description of Kalanithi´s transition from doctor to patient is pivotal. Apart from the joy of having a baby daughter shortly before his death, Kalanithi does not touch much on the meaning of personal relationships. However, he portrays the doctor-patient relationship as decisively important to him, both as a doctor and as a patient. He praises the value of having a doctor that accompanies him through his entire illness journey, and the meaning of having a continuous and trustful relationship to, in his case, an oncologist. From Lucy Kalanithi's epilogue, we learn more about the meaning of family relationships, both for her and for Paul. Here, she also describes her husband's last weeks and the way he died.

Kalanithi´s biography became popular and was reviewed in leading newspapers and medical journals worldwide. Neurosurgeon Henry Marsh said in *The Guardian* that Kalanithi *"writes very well, in a plain and matter-of-fact way, without a trace of self-pity, and you are immediately gripped and carried along"*. In *The Irish Times*, Paul D'Alton found that *"Kalanithi takes the reader into the heart of life and death. At times this is a place of brutal isolation and at times a place of the most heartbreaking human intimacy imaginable."* Ann Jurecic and Daniel Marchalik asked in *The Lancet:* When so many doctors have written about the shock of becoming patients and so many patients have written about facing death – is there more to say? Their answer is that because Kalanithi is so reflective, he has something to say and they conclude that reflectiveness should be cultivated in the medical profession, for the sake of both patients and doctors. Janet Maslin in *The New York Times* suggests: *"Part of this book's tremendous impact comes from the obvious fact that its author was such a brilliant polymath. And part comes from the way he conveys what happened to him (…)."* Kalanithi's background gives him the privileged position to tell about illness as lived experience and to be acknowledged and believed, as a doctor, patient and author.

Recognition

According to Rita Felski, *recognition* can mean both *"a cognitive insight, a moment of knowing or knowing again"* and also acknowledgement, or *"a claim for acceptance, dignity and inclusion in public life"* (Felski 2008: 29). This double meaning seems particularly relevant for pathographies. Until patients' stories started to emerge in print and on the screen, their lives and deaths had been silent to all but their close relatives. The writing and reading of pathographies brought acknowledgement of the relevance and importance of patients' and carers' perspectives, and the possibility for readers to align themselves with sick people or family carers all over the world. Patients' stories also created a possibility for physicians to enhance their understanding of what it meant to be sick, enabling them to nuance their responses towards patients. Pathografies also forefronted the important role of the caregivers. The private village of the sick became a public space, where the authors pleaded for witness and validation.

Susan Sontag coined the famous metaphor of illness and well-being as belonging to two kingdoms, and the idea of entering a different world upon becoming ill still prevails (Sontag 2002). In Paul Kalanithi's book, this is expressed in many ways, for instance where he is talking to a patient he has just realized has terminal brain cancer. The patient, however, still does not know: *"I could see the vastness of the chasm between the life she´d had last week and the one she was about to enter. She and her husband didn´t seem ready to hear brain cancer – is anyone? – so I began a couple of steps back"* (Kalanithi 2016: 93). As he himself is terminally ill, he reflects upon the identical existential disruption the diagnosis brings, reflected in the light of his previous experiences as a doctor being the one to break such news: "*Once again I had traversed the line from doctor to patient, from actor to acted upon, from subject to direct object*" (Ibid: 180). Whereas the genre of medical reports is restricted to facts and a singular perspective, Kalanithi´s statement is important as it points to unique characteristics of literature; to add several perspectives and hypothetical versions.

Through the genre of pathographies, sick people can find descriptions, metaphors and styles to express their bodily discomfort, existential anxieties and quests for meaning. Words are sought for sensations that were previously not verbalized. Literature, along with medical science, becomes not only the way to formulate the experience of having illness, but also a manner in which to rebuild the new life that remains. Paul Kalanithi, who held an MA in both English literature and medicine, writes about how this combination is literally meaning-making: "*Torn between being a doctor and being a patient, delving into medical science and turning back to literature for answers, I struggled while facing my own death, to rebuild my old life – or perhaps find a new one*" (Ibid: 139).

Literature becomes particularly important for self-formation "*when other forms of acknowledgement are felt to be lacking*" (Felski 2008: 33). Recognition in this sense means taking into account knowledge not yet fully understood, or not considered important until illness strikes. Kalanithi dwells upon this form of recognition in connection with death. As a neurosurgeon, he had close experiences with death, both communicating about it and making decisions involving the termination of life. Being terminally ill himself, he realizes that his familiarity with death has been pseudo-real: "*Death, so familiar to me in my work, was now paying a personal visit. Here we were, finally face-to-face, and yet nothing about it seemed recognizable*" (Kalanithi 2016: 121).

The experience of illness is individual, existential and lonely. The self is threatened by bodily extinction in ways that are hard to describe and share, and possibly even harder to perceive and understand for the other. "*Recognition is about knowing, but also about the limits of knowing and knowability, and about how self-perception is mediated by the other, and the perception of otherness by the self*" (Felski 2008: 49). Being bodily alone in experiencing illness can lead to a better understanding of what you are: "*The central question that symptoms can open is, Who are you?*" (Frank 1995:140). Kalanithi answers this question by claiming to be not a husband, son or future father, but a neurosurgeon. As he turns ill, his strong identity as a doctor remains. Even in part two, "Cease Not till Death", which deals with the period between diagnosis and death, professional ambitions prevail. This chapter continues to use the title phrase of the first chapter "In perfect health I begin", a quotation from the first section of Walt Whitman's famous poem "Song of Myself" (1855).

> *"My tongue, every atom of my blood, form'd from this soil, this air,*
> *Born here of parents born here from parents the same, and their parents the same,*
> *I, now thirty-seven years old in perfect health begin,*
> *Hoping to cease not till death."*

Turning to Whitman may have seemed obvious, knowing that Kalanithi wrote his MA in English literature at Stanford on the American poet. There is also a tragic irony that the lyrical voice is that of a man of the same age as Kalanithi when he is writing his book. However, the intertextual usage is primarily a way of bringing forth the aspect of recognition. It is present not only as a literary element but also as an existential means of expression, due to the presence of similar feelings across historical times. Kalanithi not only addresses his contemporary readers on today's issues but makes a point about how illness and death are recognizable despite different times, places and identities.

Knowledge

Knowledge is a theme touched upon in most pathographies, and Paul Kalanithi writes several times about his hunger for knowing how much time he has left. As a doctor, he was reluctant to be specific, e.g. informing someone that she had six months left. As a patient, he craves this information. His doctor, however, will not communicate about statistics and probability. After reflection, Kalanithi concludes that the distinction is between medical knowledge and existential hope:

> *"The reason doctors don´t give patients specific prognoses is not merely because they cannot. […] What patients see is not scientific knowledge that doctors hide but existential authenticity each person must find on her own. Getting too deeply into statistics is like trying to quench a thirst with salty water. The angst of facing mortality has no remedy in probability"* (Kalanithi 2016: 134).

Here, Kalanithi takes the perspective of the doctor, yet using a metaphorical, non-medical language. This double perspective is intriguing. David Morris writes in

Eros and Illness (2017) about how modern medicine is driven by logos instead of *medical eros*, a term coined by Morris himself, which "*[…] operates in a realm given over to uncertainty, fluidity, and profound lack of knowledge […]*" (Morris 2017: 8). Morris reflects on how medicine leaves little space for what he calls the "not-knowable", which, however, is a major part of medicine despite its preference for facts, randomized trials and objective observations. Paul Kalanithi is mentioned as an example of an author, doctor *and* patient who assigns the normally entangled different points of view to the different roles: "*He writes with deep respect for the science-based biomedical knowledge basic to his profession, but he understands too the limits of such knowledge and the importance of human affiliations that extend beyond the natural histories of disease*" (Morris 2017: 84). The attention and valuing given to human connection given by Kalanithi is complex; on the one hand, he reflects upon it in a sophisticated manner, yet the part his family and friends take in his story is clearly minor to that of his profession. Maybe Kalanithi´s Indian background, his ambitious parents and elitist education influenced his autobiographical choices. More commonly, pathographies emphasise family and friends and the role they play during illness.

Reading literature may be a method or manner of reflecting an extra-textual reality. The notion of mimesis, meaning to imitate reality, plays on the connection between the outer world and the world of fiction. Fiction is considered authentic and truthful. However, the notion of truth, according to Felski, may be problematic in connection with fiction: "*An entire cluster of terms – knowledge, reference, truth, mimesis – vanished from the higher altitudes of literary theory*" (Felski 2008: 81). In contemporary fiction, the claim to truth is not necessarily that of the majority or of the mirrored reality, but rather the subjective inner truth of the individual. The subjective rendering of personal experience of illness compared to the medical description of bodily transformations is precisely the contribution of pathographies to new ways of rendering illness. Truth may also be acknowledged in glimpses, giving the individual and art as a medium a privileged position in gaining this particular knowledge: "*Epiphany emerges as a signature mode of modernist aesthetics; the work of art discloses, makes manifest, forces into consciousness, what is otherwise inaccessible to thought*" (Felski 2008: 79). Many pathographies render this kind of epiphanic experience and the genre is often characterized as bringing particular wisdom to its readers: "*Illness narratives provide a way of knowing what really matters*" (Leimumäki 2012: 265). Kalanithi, however, explicitly challenges the myth that illness brings knowledge and certainty to the sick individual. Instead, he finds that being ill gives way to uncertainty, primarily concerning the time aspect: "*Grand il-*

lnesses are supposed to be life-clarifying. Instead, I knew I was going to die – but I´d known that before. My state of knowledge was the same, but my ability to make lunch plans had been shot to hell" (Kalanithi: 161).

Instead of clarity, stability and constancy, values and opinions are in constant motion. The lack of knowledge in Kalanithi's biography is a trait it shares with many recent patient stories. It stresses the importance of the individual and of acknowledging that truth is not necessarily only a biomedical fact but also a vague or subjective phenomenological experience of what it feels like to be ill. Moreover, it shows how pathographies, being autobiographical yet using literary devices form a genre suitable for portraying not only the biomedical facts of illness but, more importantly, the subjective experiences of being a patient.

Enchantment

"*Enchantment is characterized by a state of intense involvement, a sense of being so entirely caught up in an aesthetic object that nothing else seems to matter*" (Felski 2008: 54). This is seemingly the opposite of the widespread new critical understanding of close reading, which calls for distance and neutrality. However, Felski´s aim as such is to supplement the theoretical, skilled understanding of reading by a more pragmatical approach recognizable to the lay reader. She refers to the critic and queer theorist Joseph Boone in addressing close reading as an act that includes involvement with the other:

> "*For Boone, close reading is about intoxication rather than detachment, rupture rather than disinterestedness. […] Through the act of reading, he writes, we can experience a condition of "absolute powerlessness, enacting the intense human desire to let go – to be released, to yield to an 'other'"* " (Felski 2008: 51).

This manner of reading is crucial when dealing with patient stories; close reading takes place at the same time as involvement as a human being. While close reading often distances readers' emotions, patient stories call for an intense affective and emotional interest with the work of art. Patient stories stand out as realistic texts not fleeing reality but rather brutally confronting lived experience. Felski writes: "*Modern enchantments are those in which we are immersed but not submerged, bewitched but not beguiled, suspensions of disbelief that do not lose sight of the fictiveness of those fictions that enthrall us*" (Felski 2008: 75). The strong pathos of the pathography genre particularly calls for such a subdued reading. Felski´s distinction between old and modern enchantment may, therefore, be particularly relevant to patient stories, aiming for involvement but at the same time benefitting from some critical distance.

Enchantment is relevant to patient stories with regard to their use of other literary works or phrases. Using literary references means invoking other life stories based on aesthetic foundations. Intertextuality as a literary device manifests itself in a variety of forms, including allusion, quotation and references. In Kalanithi´s text, the use is explicit and mostly expressed in quotes and epigraphs and we have already mentioned the frequent Walt Whitman allusions. There are, however, several other examples of intertextuality, where he discusses literary works or alludes to literary references. Examples are the mention of T. S. Eliot´s "The Waste Land" (31) and some name-dropping, such as Nabokov, Conrad and Sir Thomas Browne´s *Religio Medici* (53), Nuland´s *How we Die* (52) and biblical references (164). As his condition gets worse, Kalanithi increasingly turns to literature looking for a language in which to formulate his turmoiled feelings: "*Lost in a featureless wasteland of my own mortality, and finding no traction in the realms of scientific studies, intracellular molecular pathways, and endless curves of survival statistics, I began reading literature again*" (148). "A*nd so it was literature that brought me back to life during this time*" (149). He remembers Samuel Beckett´s play "The Unnamable" (1954) and the famous end-phrase: "*I can´t go on. I´ll go on*", giving meaning and courage to Kalanithi´s hopeless situation. It is not so much literature as enchantment as a way of formulating an extra-realistic experience in which there are no words. By means of the writing process, Kalanithi experiences a certain kind of existential hope: "*Hoping is the enemy of fixity. It introduces a fluidity and even a playfulness in our construction of the world*" (Toombs et al 1995: 48).

Paul Kalanithi´s use of literature, literary references and allusions does not have an enchanting effect on the reader. Enchantment involves seeing reality through a veil of wondrousness. Pathographies like *When Breath Becomes Air* are about unveiling reality, bringing forth the brutality of being human. In doing so, the book creates a shock effect for the reader. The associations with beauty and escapism that enchantment may entail are not present when reading Kalanithi´s text. The story he presents is instead shocking: "*Shock thus marks the antithesis of the blissful enfolding and voluptuous pleasure that we associate with enchantment*" (Felski 2008: 113).

Shock

"*Shock, then, names a reaction that is startling, painful, even horrifying*" (Felski 2008: 105). "*…like a slap in the face, an exhilarating assault, equal part intellectual and visceral*" (Ibid: 106). "*…the standard supports and consolations of everyday life are ruthlessly ripped away*" (Ibid: 107). Felski's definitions of shock in literature could equally have been describing human reactions to the sudden onset of serious illness in loved ones or oneself. Becoming seriously ill is always a shock. No one, no matter what age or gender or physical condition, expects to become critically ill: "*Few people expect to enter what I have called 'deep illness', conditions that afford the person little perceived prospect of ever again living a life without some sickness or disability*" (Frank: 2000, 135).

The basis of shock is suddenness: "*Hence a common mode of beginning such books is to represent a kind of tumbling into events – the sudden phone call, the momentous X-ray, the revelation that all is not as it had to be, the breaking into one life of a calamity from another*" (Wiltshire 2000: 414). *When Breath Becomes Air* opens exactly in this manner, with a scene in which Kalanithi and his wife Lucy look at the scans which will turn his life upside down:

> "*Lying next to Lucy in the hospital bed, both of us crying, the CT scan images still glowing on the computer screen, that identity as a physician - my identity - no longer mattered. With the cancer having invaded multiple organ systems, the diagnosis was clear*" (Kalanithi: 2016, 120).

Despite the controlled and calm narrating mode, called a pause in narratology, this is the climax of the story, the turning point in both his and Lucy's lives. The shock of a fatal diagnosis is followed by several shocking moments, such as the sudden onset of diarrhoea and vomiting on graduation day and suffering from symptoms of multi-organ failure. The shocking moments are mostly rendered in a scenic manner using a calm mode. It is as the perspective of Kalanithi as a physician, his true identity as stated above, still controls his more private and devastated feelings. "*Shock pivots around the quality of what Karl Heinz Bohrer calls 'suddenness', a violent rupture of continuity and coherence, as time is definitively and dramatically rent asunder into a 'before' and 'after'*" (Felski 2008: 113). Describing and reflecting on the "before" and "after" are important hallmarks of pathographies, as are attempts at re-ordering chaotic feelings and restoring a sense of coherence. However, the feeling of shock, grief and bereavement in *When Breath Becomes Air* is less prevalent than the feeling of hard work as an ambitious neurosurgeon. Giving way to thinking about not live to see his child grow up, would presumably enhance the feelings of grief and bereavement. Keeping up with work, however, is a way of maintaining the identity he once had, being well and staying in the present tense. Kalanithi refuses to let the suddenness take over his life, and keeps up his work as a way of melting past, present and future together. Although severely ill, he still manages to return to work, thereby maintaining his mundane life despite the frailty of his body. By doing this, Kalanithi demonstrates his strategy of coping with severe illness.

It may seem odd to mention mundane life as a resonance of shock. Shock normally interferes with daily life and is not present in mundane life. Everyday life is defined by Rita Felski in this way: *"After all, everyday life simply is, indisputably: the essential, taken-for-granted continuum of mundane activities that frames our forays into more esoteric or exotic worlds"* (Felski 2008: 77). Shock and everyday life are described as opposites for most people. Shock is connected to suddenness, whereas everyday life is connected to repetition. However, recent research questions whether chronic or terminal illness necessarily has to involve shock or rupture (Ellis 2013). Having experienced the initial feeling of shock at being told they are severely ill, some patients feel that going back to daily life is the best cure. For these patients, the focus is rather on everyday life and maintaining old routines and habits. Arthur Frank wrote about this state as one of four forms of facing illness, calling it *"illness as daily life"* (Frank 2010). The sociologist Julie Ellis writes about how people facing illness and death tend to hang on to daily routines: *"What it aims to show is that a sense of continuity, a belief in pragmatism and an immersion within mundane matters of the everyday were important to families facing life-threating illness"* (Ellis 2013: 266).

Why do we read pathographies?

What are the reasons for the large interest these texts generate among readers? This is a broad question which we have discussed with reference to one particular text. We have touched upon how patient stories oscillate between enchantment and shock, between the harsh brutalities of illness and feelings of hope, dreams, escapism, looking back on better times and looking forward to being cured. Parts of Paul Kalanithi's story are placed between these antipodal positions of dread and hope, brutality of illness facts and romantic, enchanting glimpses of what life used to be like.

Paul Kalanithi´s *When Breath Becomes Air* is in many respects a *Bildungsroman* telling the story of a young man's journey from glory to defeat in the shadow of severe illness. However, Kalanithi tears down some of the myths about illness leading to wisdom, insight, and closeness to family. He is not denying but confronting (Baena 2017: 7) or, as he says himself, he is reversing the Kubler-Ross stages of grief. The use of Rita Felski's four modes of reading literature has been relevant to Kalanithi's text in many respects, illustrating the pathography genre. While stressing the aspect of shock, he gives a true, yet uncomfortable version of what it is like to be terminally ill at the age of 36. He lived the dream but ended up in the nightmare we all want to avoid. The shock of illness does not lead him to greater insight, but to enhanced attention to life.

"As long as we find ourselves prone to evasion, euphemism, and denial, as long as we flinch away from reminders of our material and mortal existence as fragile composites of blood, bone and tissue, shock will continue to find a place in art" (Felski 2008: 130). The popularity of pathographies of various genres, however, indicates a broad interest in topics that do remind us of our mortality. Deep beneath the civilized and sugar-candied surface, we do have an awareness of being creatures of flesh and blood. Irrespective of gender, cultural background, ethnicity, age or social status, these texts render the experience of being human. Doctors are well represented in writing pathographies (Aronsen 2000), even though the majority is written by patients not having a professional medical perspective. Perhaps it is due to the imminent paradox of the ill doctor that these books, like Kalanithi´s own, gain such popularity.

So why *do* we read pathographies? What Rita Felski claims as a general description of work of art could equally well have been a poignant description on the peculiarities of pathographies: *"Rather than serving up suffering at a distance, they allow us to witness it close up, magnified to the nth degree, sometimes in lurid and blood-spattered detail"* (Felski 2008: 114). This is true of many first-person accounts about illness, including *When Breath Becomes Air*. Paul Kalanithi becomes close to us. We align with his ambitions, hope for him to succeed, and are shocked by the brutality of his tragedy. This pathography bears the mark of a Greek tragedy, bearing resemblance to Icarus and the theme of hubris. Kalanithi is almost too successful until illness strikes him down. The central function that shock bears in pathographies stresses the resemblance between the genre and classical Aristotelian tragedy: the rendering of a tragic hero making a fatal mistake due to a tragic flaw and thereby suffering an ill fate. A crucial part of classical tragedy is that the incidents are most often beyond the hero's control, a similarity it shares with pathographies. Ill health and serious diseases are in many cases purely the result of bad luck. Like the readers of Greek tragedies, we are perhaps not only shocked but also cleansed by the shock having had the effect of *catharsis*. The feeling of shock, so central to Kalanithi himself, is transported to us as readers, as are the feelings of recognition, knowledge and enchantment. *When Breath Becomes Air* arouses all these feelings in the reader as well as in the protagonist – on a most profound, existential level. The story of the patient is a genre in which an impressive multiplicity of reader-response is awakened and alarmed. This lays the ground for a strong feeling of empathy, close to identification, with the author-protagonist, which may be one of the reasons for the popularity of the pathography genre.

References

Aronsen, J.K. (2000). Autopathography: the patient's tale. *British Medical Journal*, 1599-1602. https://doi.org/10.1136/bmj.321.7276.1599

Baena, R. (2017). Narrative empathy and illness memoirs: Arthur Frank's At the Will of the Body and Kathlyn Conway's Ordinary Life. *Medical Humanities, 43(3)*, p.177. https://doi.org/10.1136/medhum-2016-011052

Bernhardsson, K. (2010). *Litterära besvär. Skildringar av sjukdom i samtida svensk prosa* [Literary problems. Descriptions of disease in contemporary Swedish prose]. Stockholm: Ellerström.

Du, H. & Wagner, C. (2006) Weblog success: Exploring the role of technology. International Journal of Human - *Computer Studies, 64(9)*, 789-798. https://doi.org/10.1016/j.ijhcs.2006.04.002

Ellis, J. (2013). Thinking beyond rupture: continuity and relationality in everyday illness and dying experience. *Mortality*, pp.1-19. https://doi.org/10.1080/13576275.2013.819490

Ezzy, D. (2000). Illness narratives: time, hope and HIV. *Social Science & Medicine, 50(5)*, pp.605-617. https://doi.org/10.1016/S0277-9536(99)00306-8

Felski, R. (2000). *Doing time: feminist theory and postmodern culture*, New York: New York University Press.

Felski, R. (2008). *The Uses of Literature.* Blackwell Manifestos, Oxford, UK: Blackwell Publishing Ltd. https://doi.org/10.1002/9781444302790

Frank, A.W. (2000) Illness and Autobiographical Work: Dialogue as Narrative Destabilization. *Qualitative Sociology, 23(1)*, pp. 135-156. https://doi.org/10.1023/A:1005411818318

Frank, A.W. (2010). *Letting stories breathe: a socio-narratology*, Chicago, Ill: University of Chicago Press. https://doi.org/10.7208/chicago/9780226260143.001.0001

Frank, A.W. (2013). *The wounded storyteller: body, illness, and ethics* 2nd ed., Chicago, Ill: University of Chicago Press.

Gamerman E. (2016). A Book on Life and Death Becomes a Best Seller. *The Wall Street Journal, 19* Dec. https://www.wsj.com/articles/a-book-on-life-and-death-becomes-a-best-seller-1482167354 Retrieved 18 Nov 2018.

Hawkins, A.H. (1999). *Reconstructing illness. Studies in pathography* 2nd ed., West Lafayette, Ind: Purdue University Press.

Guardian, The (2016). »*Lucy Kalanithi: 'Paul's view was that life wasn't about avoiding suffering'*«. Interview by Lisa O'Kelly. Read 25 June 2018.

Horst, C. auf der (2004) »Historisch-kritische Pathographien und Historizität: Eine Kritische Auswertung der Heine-Pathographien am Beispiel Der Syphilisdiagnosen Heinrich Heines.« *Sudhoffs Archiv. Zeitschrift Für Wissenschaftsgeschichte. Beihefte, no. 54:* 121-51. https://www.irishtimes.com/culture/books/when-breath-becomes-air-review-a-neurosurgeon-s-story-of-terminal-illness-1.2933276

Kalanithi, P. & Verghese, A. (2016). *When Breath Becomes Air* 1st ed., London: Random House.

Lekmumäki, A. (2012). What does falling ill mean? Illness experience as elucidation of experience expertise. In: Cohen, E. *Knowledge and pain*, Amsterdam: Rodopi. https://doi.org/10.1163/9789401208574_014

Mattingly, C. (1994). The concept of therapeutic emplotment. *Social Science and Medicine, 38*, 811-822. https://doi.org/10.1016/0277-9536(94)90153-8

medscape.com/viewarticle/865258

Morris, D.B. (2017). *Eros and illness*, Cambridge, MA and London, England: Harvard University Press.

nytimes.com/2016/01/07/books/review-in-when-breath-becomes-air-dr-paul-kalanithi-confronts-an-early-death.html

sciencedirect.com/science/article/pii/S0140673616006656 (The Lancet)

Sontag, S. (2002). *Illness as metaphor and Aids and its metaphors*, London: Penguin Books

theguardian.com/books/2016/jan/31/when-breath-becomes-air-paul-kalanithi-review

thelancet.com/journals/lancet/article/PIIS0140-6736(16)32470-9/abstract

Tjora, A. & Sandaunet A.G. (2010). *Digitale pasienter*, Oslo: Gyldendal akademisk

Tooms, K., Barnard, D. & Carson, A. (Eds) (1995). *Chronic illness: From experience to policy* (p. 221). Indiana University Press.

Wiltshire, J. (2000). Biography, pathography, and the recovery of meaning. *Cambridge Quarterly, 29(4)*, pp. 409-22. https://doi.org/10.1093/camqtly/XXIX.4.409

Originalartikel

The Writer as a Patient with a Brain Tumour

A Comparative Study

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This article main concern is how professional authors and intellectuals develop illness narratives addressing the experience of having a brain tumour, and how this condition resorts to specific narratological features. Unlike pathographies written by laypersons, autobiographical accounts of illness developed by writers, and intellectuals create a narrative subjectivity that is specifically linked to their professional status rather than to their patient status which is simultaneous with the narrative time. In this article, we analyse two autobiographical novels, addressing the experiences of two European authors and intellectuals suffering from a brain tumour: A Journey Round My Skull (1939[1937]) by Frigyes Karinthy and Until Further Notice, I Am Alive (2012) by Tom Lubbock. These narratives on illness processes related to brain tumours are a place where writers resist the main symptoms and outcomes of this specific disease that, while affecting their cognitive capacities, seem to deprive them of their self-image as writers. Hence, these writings are based on the realignment of their past and present identities (Rimmon-Kenan, 2002: 15-18) always in connection with their images as authors. The comparative analysis presented here is intended as a contribution from the field of literary studies to the understanding of subjectivity in patients, whose narratives are not written to seek cure or to search for a

cause or meaning for the disease, but to fight the loss of the writer-patient creative identity and 'ipseity' (Derrida, 2009).

Introduction

As suggested by Bishop in *The Genius of Disease*, a series of brief articles published in 1993-1994, suffering from a brain tumour implies an undeniable fear: during the course of the disease, both patients and their closest relations may start doubting and questioning their thinking (Bishop, 1994). This is what Bishop also defines as an *"altered state of consciousness"* (Bishop, 1994:2); particularly linked to the specific condition of these patients that can be tracked in their narratives. This distinct symptom and disability indicator of brain tumours are undoubtedly one of the most sensitive ones within patients, that work and define themselves as professional writers and artists, because their capacity for thinking and creating through symbolic languages is in question. In this article, I analyse two autobiographical novels addressing the experiences of two authors and intellectuals suffering from a brain tumour: *A Journey Round My Skull* (1939[1937]) by Frigyes Karinthy and *Until Further Notice, I Am Alive* (2012) by Tom Lubbock. Both texts fall into the umbrella term of "illness narratives" as they are "autobiographical accounts of illness spoken or written by patients" (Jurecic, 2012:2).

In his fundamental work *Illness Narratives: Suffering, Healing, and the Human Condition* (1988), Arthur Kleinman created a paradigm where narratives formulated by patients acquired a central role to produce a detailed clinical image of the patient, and in delving a productive healing relationship. In contrast to writings having illness as their background or topic, illness narratives have the personal illness experience at heart, and they include some grade of factual examination about the outcomes that patients have had on their own lives since diagnosis (Bury, 1982; Frank, 1995).

As the documented research has shown, narratives written by ill and disease subjects are far removed from the brand of autobiographical writings, and form a category of their own (Brody, 1987; Frank, 1995; Hawkins, 1984; Kleinman, 1988). If "life writing" (Bradford, 2009; Preece et al., 2007) has traditionally posed critical questions on the frontiers of literature, illness narratives further reframe this debate. They demand a reflection about the ways of inscribing the ill-self in the narrative, because they frequently avoid countersigning to one specific reading, such as the dominant biomedical one (Frank, 1995).

As Shapiro has suggested, a patient's story is never "just a story"— this complexifies the narrative defying the reader's expectations of reliability and authenticity (Shapiro 2011). The texts discussed in this article show no ambiguity, alter-egos or experimentation with the "I" figure and voice within the writing. In doing so, they inscribe themselves under the illness narrative concept, which certainly includes biographical and autobiographical accounts of illness (Hawkins, 1999b). Moreover, in our study cases there is a clear identification between the author's name and the main character: the "patient". The narrative in these novels seeks to establish and highlight that the main character, and narrative voice, is both a patient of a disease affecting his cognitive intelligence, and the professional writer whose name is on the book's cover. Since the very beginning of the two books, this identification enables both writer and reader to make an autobiographical reading pact or contract (Lejeune & Eakin, 1988) based on the equivalence between the two figures and their names (the public writer and the narrator/protagonist), and to explore the implications resulting from this equivalence.

Unlike *pathographies*, which are mainly developed by laypersons (Hawkins, 1999a), autobiographical accounts of illness, formulated by writers and intellectuals, create a narrative subjectivity specifically linked to their professional status rather than to their patient status, which is simultaneous with the narrative time. In making claims for the relevance of the professional writer as patient within the large corpus of illness narratives, Peter Graham has proposed the concept of *metapathographies* for this subgroup, considering these narratives

> *"not simple personal stories of illness but artful transformations of the genre, works whose authors, relying on the distinctive professional strengths at their disposal, write themselves out of illness and suffering and do so, finally, by looking past pathography itself"* (Graham, 1997:73).

Graham's observations on the subject confirm the outstanding importance of taking into account, when authors of illness narratives are professional authors and intellectuals before receiving the diagnosis. When authors within this subgenre are professional writers and intellectuals, illness narratives addressing the experience of having a serious disease use specific narratological features to develop the story.

Although, medicine has appreciably improved since Karinthy's case in the first half of the 20th century, and it is now offering new and more innovative techniques to treat patients of brain tumours, it often ignores many of the concerns and needs of sick people related to the specific illness they are suffering and to their distinctive context. Confirming the aforementioned hypothesis of Bishop's article, the illness narratives that I take in my study reflect a specific harm and suffering of the brain tumour patients: the loss of their capacities and condition as professional writers. Thus, both Kartinthy's and Lubbock's novel reinforce previous studies on chronic illness as a biographical disruption, which can be traced as a constant *motif* in semi-structured interviews with patients (Bury, 1982), as well as in literary narrative works dealing with personal illness experiences (Cantabrana et al., 2016). Following narrative critic Rimmon-Kenan, the patient-writers in my corpus assume (whereas consciously or unconsciously) that the continuity of their past, present and future as active artistic subjects are destabilized by the disruption of a disease (Rimmon-Kenan, 2002:12) which turns them into ordinary laypersons and disconnects them from their self-image as writers during and after the disease. While describing other cases, Rimmon-Kenan suggests something that is particularly accurate to the narrative of biographical disruption (Bury, 1982), that both Karinthy and Lubbock have brought to their *illness narratives*: *"reading and writing, a professional necessity as well as an existential passion, have become virtually impossible"*(Rimmon-Kenan, 2002:10). In this sense, brain tumour and brain cancer impel new and relevant meanings in comparison to other diseases within illness narratives written by professional writers.

The selective nature for my study cases, *A Journey Round My Skull* and *Until Further Notice, I Am Alive* includes historiographical, geographical, thematic and literary aspects. As the aforementioned critical discussion has shown, they both fall into the illness narratives category and, hence, in the perspective of an actual patient. The general aim was to concentrate in brain tumour narratives written by professional authors, because of the quintessential symptomatic range of this disease that disqualifies the subject-patient as a writer and/or intellectual. The relevance of Karinthy's novel, *A Journey Round my Skull*, lies not only on the multiple narrative features of the text and on the focalization on his own illness process but also on its publication date. To that date (1939), complete autobiographical novels on illness experiences were not so frequent, especially in comparison to the nowadays growing number of autobiographical novels on serious illnesses, as cancer. As stated by Anne Hunsaker Hawkins, book-length pathographies are not very common *"before 1950 and rarely found before 1900"*(Hawkins, 1999b:3). On the other hand, Lubbock's novel has had a widely positive reception, in terms of literary quality it outstands from many other autobiographical novels on brain tumours, and is also nowadays a frequent reading recommendation for those subjects suffering from a brain tumour.[1] While both together are European novels and refer to a contemporary world (from a symbolic point of view), their differences between geographical location and publication date (they are 75 years apart), enable a productive comparative analysis.

Our research question is: that narratives about brain tumours are a place where, while writing, professional authors resist the biographical and subjectivity fracture that happens after becoming patients of a disease, that normally deprives them of their creative and cognitive capacities. Instead of focusing on the health-disease pair, their writings are based on the realignment of their past and present identities (Rimmon-Kenan, 2002: 15-18), which are always linked to their images as authors, writers, and intellectuals. Therefore, the narrative searches for an image of themselves self as *active* artists, we may say, and not as patients. Focusing the analysis of the two novels on the autobiographical pact and on general narrative strategies and techniques, this article aims to examine the strong link between certain diseases' symptomatology and the narrative subjectivity built by patients. Finally, this comparative analysis is intended as a contribution from the field of literary studies to the understanding of subjectivity in writers as patients, whose narratives are not written to seek cure or even to search for a cause-reason to their disease, but rather to fight the loss of their creative identities and 'ipseities' (Derrida & Bennington, 2009), which due to diagnoses, therapies, increasing symptoms and hospitalizations seem to be at stake.

Frigyes Karinthy's *A Journey Round my Skull* (1939)

Although many of us might not be very familiar with his name, Frigyes Karinthy was a very successful and prolific Hungarian author. He was born in Budapest in 1887 and died from a stroke in 1938, just one year before *A Journey Round my Skull* was published. As the title of the novel may anticipate, he was indeed a great admirer of Jules Verne. He published his first novel at the age of fifteen. He studied medicine and science at the University of Budapest, and after university he started working as a journalist while getting into the café society of the great Hungarian capital. Eventually, he wrote many other books and texts of different genres, including poetry, short stories, and theatrical pieces. Also, he became an influential person within the Hungarian intellectuality and got a name as a humourous writer.

The café society was the main *milieu* for the multiple changes and the Modernity rising in Europe at the end of the 19th century and the beginning of the 20th century. By the turn of the century, there were hundreds of cafés in Budapest, where writers, painters, philosophers and poets gathered around, sharing beverages while having lively conversations, and discussing the main agenda of intellectuality. These cafés were the infrastructure of modern cultural sociability. Although this type of social gathering at a public place was not formal, and only had as its main subject the discussion of current affairs while having a beverage, it was actually the place where most of the next-generation European artists were making a path. It is not a surprise, indeed, that Karinthy had recognized the very first symptoms of his disease while being at his favourite café. As he says in the first chapter of his novel *The Invisible Train*, he started having auditory hallucinations or sudden losses of consciousness: *"And at that very moment the trains started. Punctually to the minute, at ten past seven, I heard the first one"* (Karinthy et al., 2008:12). However, even without knowing that the source was a tumour he recognized the abnormality of the symptoms, and that they were not related to a psychological issue: *"I could not have gone mad for, in that event, I should be incapable of diagnosing my case. Something else must be wrong."* (Karinthy et al., 2008:14)

In addition to the hallucinatory train noises that became a constant presence, other manifestations of the tumour would get into his daily routine too. From this point, the narrative of *Journey Round my Skull* traces the path from the first symptoms of the brain tumour, through the different diagnoses, to the final verdict, including a highly complicated surgery in Sweden.

> *"The mirror opposite me seemed to move. Not more than an inch or two, then it hung still. [. . .] But what was happening now?*
> *What was this —queer feeling—coming over me? The queerest thing was that—I didn't know what was queer. Perhaps there was nothing else queer about it. Yet I was conscious of something I had never known before, or rather I missed something that I had been accustomed to since I was first conscious of being alive, though I had never paid much heed to it. I had no headache, no pain of any kind, I heard no trains, my heart was perfectly normal. And yet […]"* (Karinthy et al., 2008:32–33).

Throughout the illness period as narrated in the novel, Karinthy persistently tries to hide his agony, the increasing disability marks generated by the specific location of the tumour, and he is frequently mistrustful towards his beloved ones and towards his medical practitioners. Not surprisingly, this attitude is not a resistance to the actual illness; he is not denying his ill condition. However, it seems as a resistance to being treated as a wounded and ill subject that has lost his most valuable identity trace, the one related to being an *author* as an (intellectual) *authority* in the first half of the 20th century. In another episode, again situated in a café, we reach a deeper understanding of how his narrative subjectivity as writer/patient is constantly negotiated in regard to his socially constructed image as a writer:

> *"[…] I took out my watch and laid it on the table.*
> *'Give me some morphia,' I said in a calm, hostile, icy tone.*
> *'You mustn't take morphia! You know perfectly well. The very idea! And what are you doing with that watch?'*
> *'You will give me morphia within three minutes.'*
> *They looked me uneasily up and down. No one moved. Three minutes went by. Then ten more. I slipped the watch calmly into my pocket and rose unsteadily to my feet.*
> *'Then take me to the Fiakker Bar. They say it's a good show, and tonight I want to enjoy myself. '*
> *The others jumped up with a feeling of relief.*
> *I never confessed the secret to anyone, either then or afterwards. I had made up my mind at the end of those three minutes —for the first and last time in my life— that if my headache had not stopped within the next ten I should throw myself under the nearest tram.*
> *It never came out whether I should have kept to my resolve, for the pain left off with the suddenness of lightning."* (Karinthy et al., 2008:132).

In Karinthy's novel, the space of the cafés should not be underestimated in terms of the construction of a narrative subjectivity linked to the artistic subject idea. In this particular passage, the patient/writer character is at the Café Paris in Vienna, where he goes to be diagnosed and treated of his pathology, surrounded by the social group to which he belongs: artists, intellectuals, journalists, and writers. By the end of the passage, we learn that his abrupt petition of morphia has to do with the aggravation of his symptoms. His headache was getting worse and worse to the point that he even wanted to die. Yet the narrative shows, that he interacted with his friends and acquaintances in an odd manner, without explaining what was going on. He would not share the truth of his condition with the surrounding subjects, and he finally resumed the interaction humorously asking to go to another bar.

Acknowledging his symptoms in this particular public space, surrounded by this specific *milieu*, would have meant to accept the disruption, the narrative subjectivity disconnection that Rimmon-Kenan has noted down for illness narratives. Expressing his pain, manifesting his illness, would have meant to refuse his status as a writer, thinker and artist afflicted by spiritual and intellectual matters (not physical ones), a symbolic master narrative of his own, which apparently he was not ready to abandon. The level of the story puts together many other situations, where Karinthy' character masks the shortcomings and sufferings of the body with the redemption of the spirit and the mind:

> *"By now, I had learnt to interpret every hint afforded by the shifting of light and to complete the general effect from memory. I was getting used to this strange semi-darkness in which I lived, and I almost began to like it. I could still see the outline of figures fairly well, and my imagination supplied all the details, like a painter filling an empty frame. I tried to form a picture of any face I saw in front of me by observing the person's voice and movements.[. . .] I stood on the threshold of reality and imagination, and I began to doubt which was which. My bodily eye and my mind's eye were blending into one."* (Karinthy et al., 2008:188–189)

These are Karinthy's words when the doctor stays staring at him, because he has finally realized that a brain tumour is causing his symptoms: *"I had suddenly become a stranger to him"* (Karinthy et al., 2008). It is not a negotiation between illness/disability and health that is displayed in many sequences of the novel, but the negotiation between being a writer and being a subject suffering from a brain tumour; a negotiation against becoming a body of disease and losing his creative self.

Tom Lubbock's *Until further notice, I'm alive* (2012)

Tom Lubbock was a British writer, art critic and journalist. In the words of his wife's introduction to his last book:

> *"[…] a writer about art, a critic and an illustrator who worked with images, creating the collages which appeared weekly between 1999 and 2004 on the editorial page of* The Independent*, and intermittently since then"* (Lubbock, 2012).

To say that his novel *Until further notice, I'm alive* is about his fight against cancer is to come short at properly analysing this piece of illness narrative. Using the first person and chunks of a diary, Lubbock describes and follows each step of his suffering during the illness, specifically focusing on how he loses his ability to handle words, to create with words, and his inability to communicate with others. As Gregor Samsa at the beginning of *Die Verwandlung* (1915), finds himself suddenly transformed into another living being, one that feels strange to his own self; Tom Lubbock got unsettled about himself while realizing that his speech was *"becoming a radical problem"* since the diagnosis. A very talented and loquacious man found himself deprived not of life, because that is not what is actually missing in his novel, but of his more precious subjectivity trademark, his ability to express, describe and create beauty with words: *"The good of the world includes my unique way of experiencing it, and for me that is almost all"* (Lubbock, 2012).

Lubbock's original text was first published in an English newspaper, *The Observer*, in 2010. The novel was also published in 2010, after Lubbock's death, and contains the original article along with entries from the journal that the author started writing shortly after his diagnosis and the realization that he was losing part of his verbal capacities. Framing a text with a note from a relative or close person to the deceased person is a common tool within narratives going through the final stretch of a person's life. In the case of Lubbock, this note is an introduction by Marion Coutts, his wife, who is constantly mentioned in her husband's narration, along with his little son, Eugene. Moreover, Lubbock's uses the first plural person in many passages, erasing the strong "I" typical of this type of narratives, and confirming the hardness of this process in his private circle his family.

Lubbock spends many pages dealing with a paradox, putting into words how he becomes deprived of his ability to formulate with words. He insists on perceiving this dysfunction as an abnormality turning him into a different subject; one who is no longer able to master a basic human function, the one of language:

> *"For me, no word comes without a prior thought. No sentence is generated without effort. No formulation is made automatically. I am faced practically and continually with a mystery that other people have no conception of, the mystery of the generation of speech"* (Lubbock, 2012).

In a few other passages, Lubbock's narrative displays this aspect of his disease, as a clear detachment from his prior self, as a writer who could master the art of language:

> *"Sometimes I feel that I am not quite well now, in relation to language, and then I want to know what is wrong; sometimes I feel I'm fine, and I want the results to be fine as before. I am as usual becoming fearful."* (Lubbock, 2012).

The loss of language goes systematically together with the experience of othering from him (self).

Knowing its prognosis and life expectancy from the outset, Lubbock's text is constructed under the structural principle of the experience of a patient dying from a terminal illness. It builds a narrative line that has a theological orientation about life and death; it exhibits a painful but marked will to move forward to a recognized end that implies the death of the author and, within the narrative, the death of the character. However, this doesn't always work as clearly. The very same disruption of illness that tackles the past-present-future continuity projecting the narrative subjectivity only to the future, and to the end of disease, sometimes stops. This creates a new form of disruption of illness; a new unexpected pathway that must be accepted:

> *"When you get a cancer diagnosis, the story is expected to have two options. Either there is an ending with death. Or there is an overcoming. And both are satisfactory conclusions. But prolongation, unclear survival, is also a familiar narrative form. There is the shaggy-dog story that I and my family live in. Likewise, this hope for speech. The tale is spun out, with an ending wanting to be endlessly deferred."* (Lubbock, 2012).

Although, the pause in the continuity to the future of the patient means attaining stability in terms of the disease, this equally affects our writer/patient subjectivity, who in these moments foresees the challenge of being present-oriented. Hence, this means perceiving as normal and constant the biographical and cognitive shifts that come with the illness. The new disruption in the past-present-future continuity brings about a new split in temporality, and creates what Marion Coutts defined in *The Iceberg* (2014), her own narrative of Lubbock's disease, as *"Being stuck in the present"* (Coutts, 2014). The present of the illness.

Subjectivity Disruption and *Othering* in Illness Narratives from Professional Writers

"I cannot describe myself in words." (Coutts, 2014)

These narratives significantly benefit from the question of loss of a subjectivity trait in relation to the artistic profession through the process of disease; the focus in this loss shoots and moves the narrative plotline; in a way which is much more powerful than making a detailed description of the physical pain suffered, or than delving into a death prognosis. Clearly, Karinthy as well as Lubbock, show in their narratives how the transition from being a writer to being a patient with a brain tumour implies a developing disability that deprives them of a subjectivity trademark. In this sense, their narratives confirm Bury's point on chronic illness as biographical disruption: *"illness […] is precisely that kind of experience where the structures of everyday life and the forms of knowledge which underpin them are disrupted"* (Bury, 1982:169). As other shared narratological feature, both illness narratives discussed above achieve a *textual empathy* and not *empathy based on proximity* (Schmitt, 2017:121), or by identification with the life of the main character. Using various narrative resources, the textual empathy developed in the novels is based mainly on a narrative of an accomplished writer losing what he portrays as his artistic subjectivity while being a patient. Therefore, not only physical pain, fluctuating symptoms and uncertain outcomes, but also the question of why are not primarily focalised in both novels. On the contrary, the fluctuation of cognitive capacities that legitimize both subjects-protagonists as accomplished writers, how this disturbs the image of themselves, and the relation with the others take the narrative.

There is no essentialist view of the writer-patient identity in these narratives. On the contrary, as Rimmon-Kenan suggests, the "narrative identity" built in the text and the features deployed therein should be observed. In the case of Karinthy, the narrative builds a writer's identity that is socially perceived and recognized as such. The novel begins with the first symptoms in a relevant space for the modernist intellectual *milieu* and with an equivocal diagnostic process that lasts almost half of the novel, until the chapter "The Verdict". The disruption of the disease seems to inquire and put into play the narrative subjectivity of the writer that appears on the first pages. The manifestation of disease is the starting point from where the character/author/patient will try to negotiate between his (self) recognition of a writer's subjectivity and his patient status along the narrative. *Jour-*

ney Round My Skull is riddled with notes, descriptions and comments on how the patient disguised his illness or avoided acknowledging his patient status within the presence of his illness. In spite of the fact, that ignoring, hiding and denying attitudes are a documented structural part of the classic sick-role behaviour (Bury, 1982), Karinthy's plotline should always be read as the search to reaffirm a narrative subjectivity as a socially recognized writer. In addition, the novel also portrays with extreme detail how the rest of the contemporary, and mainly Hungarian, society reflected and followed the process of Karinthy's illness, which is intended to be read as the illness of a recognized and relevant intellectual figure.

In the chapter *Let His Bonds Be Loosened* of Karinthy's novel, we find again the presence of this narrative configuration of disease in relation to the subjectivity of the accomplished and renowned author-intellectual. The writer/patient is at rest, after the successful completion of the brain tumour operation in the Swedish hospital, and he receives the visit of his doctor, Olivecrona, who asks him *"Who are you in your own country?"* (Karinthy et al., 2008:270). As reported to Karinthy, Olivecrona has received in recent hours a myriad of notes and calls from people in Hungary thanking him for saving this renowned patient. While in Sweden, Karinthy is a just another patient of a complicated medical case anonymized by the barriers of the hospital institution, in Hungary he is a well-recognized intellectual figure, whose ailment has become a national matter. In the same chapter, after the doctor leaves the room, the character-patient recites in a soft voice and with minimal modifications the poem *"Die Heimkehr"* (1824) by Heinrich Heine, which reaffirms his identity as a recognized writer, even when he is lying in bed after major surgery and some signs of disability due to the disease: *"Ich bin ein … Dichter/ Bekannt in ... Land/ Nennt man die besten Namen/ So wird auch der meine gennant."* (Karinthy et al., 2008:271)[2]

On the other side, Lubbock begins his illness narrative from the beginning, which in medical terms is with the illness diagnosis in the first chapter, "A Piece of News". The main character/narrator wakes up in a hospital, after undergoing tests and scans that confirmed he had a stage four brain tumour. There is no narrative positioning on the level of the story as mainly a socially recognized writer, as there is in Karinthy's novel. Moreover, as we mentioned before, he sometimes uses a plural voice, displacing a strong individual voice as a writer, and he includes other people in the narrative constructions, creating a strong sense of sharing but in an intimate way. Instead, in Lubbock we found the exploration and inquiry around another element that has to do with a writer's narrative subjectivity: the loss of the ability to master every competence related to verbal language. This form of disability is what takes most of the narrative in Lubbock's novel, who is in a moving point of the book, after going under an operation notices that his speech and words are falling away. Accordingly, the twilight of the writing and verbal skills are coincidental with the last living moments of the writer/patient. And once again, as in Karinthy's case, we find poetry as a form of resistance of the narrative subjectivity in the most difficult time of the illness process:

> *''My true exit may be accompanied by no words at all, all gone.*
> *The final thing. The illiterate. The dumb.*
> *Speech?*
> *Quien but still something?*
> *Noises?*
> *Nothing?*
> *My body. My tree.*
> *After that it becomes simply the world.''* (Lubbock, 2012)

These constructions of the narrative subjectivity identify as one of a writer with a brain tumour have different results at the story level. Karinthy chooses to construct a plotline that uncovers the constant need to battle the patient condition of the main character, reminding his position as a famous writer and hiding his symptoms on several occasions. In other words, Karinthy constructs a story that shows how the character/patient avoids confronting the "Altered state of consciousness" resulting from the brain tumour. Accordingly, the spaces where the plotline unwraps are mainly public, as the city cafés. Whereas Lubbock, who writes while the disease develops, puts the main symptoms in the foreground, especially those related to the confusion and loss of command and consciousness that Bishop pointed out in the aforementioned article. Lubbock constructs a narrative discourse that is, in fact, a resistance to the story level. While in the story level, Lubbock is losing his speech abilities, in the discourse level he is gaining words. Parallel to the patient's aphasia story, Lubbock creates a narrative text in the form of a novel, which is the actual confirmation of his narrative subjectivity as a writer, in spite of his symptoms due to the brain tumour. Consequently, the main spaces of Lubbock's illness narrative are private (as his own home) and internal (as his writing).

The temporal perspectives used in these two novels are quite different. While Karinthy writes after his operation and recovery, Lubbock writes during his fatal disease process. In Lubbock's novel, the present of the narration is equivalent to the present of the experience. That's what Rimmon-Kenan calls the "simultaneous present" (Rimmon-Kenan, 2002:20) When taking together the illness narratives depicted in these novels, we can notice they have one point in common in terms of temporality: the disruption of disease in the previous present-past-future continuity produces a dislocation of the narrative identity in both writers and, thus, an absence of *prolepsis* and *analepsis* (Genette, 1980:40). This is, the narrators do not anticipate or evoke a healthy state that will occur after the main part of the story (the terminal disease process) ends. The disease casts a faint shadow on the identity as artists and intellectuals they had before the diagnosis, and they try bringing it to the present through narrative. Their narrative subjectivity as writers and the temporality used to build them are therefore dependent on one event: the emergence of the disease and its subsequent displacement. Moreover, if there is any *analepsis* and projection to an anachronistic past existing before the condition appeared, as Rimmon-Kenan points out, this appears in a non-central way (Rimmon-Kenan, 2002:20). The overwhelming present pervades it all, both in the story and in the discourse levels.

In practical terms, the chronic and terminal disease introduces patients to a completely new world that must be assimilated quickly, and has to do with the hospital apparatus: being taken care of by others, becoming the object of medicine and the health system. In symbolic terms, as we have already introduced in the texts of Karinthy and Lubbock, the patient's character is confronted with the self-consciousness of his own alterity that disrupts and dislocates a narrative subjectivity built as a writer. As patients, these characters face and turn into an *otherness*. That *otherness* is the one that confirms and remains the pre-existence of their *selfhood*, their 'ipseity', using a term Derrida takes from Heidegger:

> *"The definition that Heidegger then gives of the ipseity of the self-same* (das "sich selbst") *is linked to this effractive departure from self in order violently to break open, to capture, to tame* (Ausbrechen, Umbrechen, Einfangen, Niederzwingen). *It is through this violence that breaks open ground or path, captures, tames, that beings are discovered or revealed or unveiled."* (Derrida & Bennington, 2009:395)

The writers' 'ipseity' appears disaggregated in the narrative of these novels by the appearance of a disease affecting the specific pillars of their creative and artistic lives, leading to their condition of patients and, accordingly, laymen. Derrida retains the sense of difference and 'ipseity' existing within the uniqueness or subjectivity of an individual's own perception of the *Other* and *vice versa*. For Derrida, the big question of 'ipseity' is intrinsically attached to sovereignty in terms of the possibility of *selfhood*. In this sense and in the framework of our study, the 'ipseity' is linked to the narrative identity of being a writer, and the otherness is linked to the narrative identity of being a patient. Beyond the State sovereignty, which is indeed of great importance for Derrida, we should consider these illness narratives as auto-positions of selfhood by the writer/patients, of their power to be singular selves.

Concluding remarks

In describing, discussing and comparing the illness narratives of Frigyes Karinthy and Tom Lubbock, I tried to contribute to the understanding of a distinctive group of cancer narratives, giving to contextual criteria and literary features a main role.

As a point of departure, I took the category of *illness narratives* originated by anthropologist Arthur Kleinman. Although I agree with both books, we are indeed confronted with illness narratives. I have found a main concern in my corpus that is not completely represented in Kleinman's observations. *In his The Illness Narratives: Suffering, Healing and the Human Condition* (1988), Arthur Kleinman points out that the disease person and his/her social entourage almost always pose the question of *why* (Kleinman, 1988). As the analysis and discussion have shown, this is not a relevant question in the illness narratives of Karinthy and Lubbock. As shown in the analysis, when dealing with brain tumours, illness narratives compromised plenty narrative features that tend to stand out the literary and artistic subjectivity of the author. Thus, the question of *who*. Instead and following Bury's (1982) and Rimmon-Kenan's (2002) contributions, I have shown the disruption aspect of disease is central in these narratives in terms of the biographical traces of the implied subjects. On top, the narrative features of these illness narratives contribute to show not only that the disease does not write the subject-patients, but also that it does not prescribe the subject-writer to follow the normal pathways of dealing with a serious disease. Moreover, the narrative space becomes the place to negotiate a writer's subjectivity that resists with words and with an artistic production the progress of disease.

As readers of these two illness narratives, we tend to empathize with these authors/patients not mainly because of the physical suffering of the disease, but mostly because they delve into an internal reality conflict that rises after becoming a body of illness, a body of medicine and, particularly, a body of a disease that affects mainly the cognitive capacities related to being a writer and an intellectual. The narrative resources they both use tend to guide the reader in this direction. The question is: Who is the sovereign of an ill-body going through illness under modern biomedical treatments? Even more: Who is the sovereign of the ill-subject's narrative? Illness narratives of professional writers become a space for negotiating two narrative identities that are described as being incompatible in cases of brain tumour: the one of being a patient with endangered cognitive and creative abilities and the one of being a writer. And, as we have discussed, brain tumour disease symptoms play a central role in that interaction as a violent rupture recalling the sovereignty of the self as an artistic subject.

Notes

1. A quick internet research will confirm this. Many websites related to brain tumour organizations and institutions, as for instance the *"Brain Tumour Research"* website, list Lubbock's book within their recommendations.
2. The English translation of Karinthy's novel quotes Heine's verses in German as the transcription above. The complete text in German, without Karinthy's meanted omissions, is: *"Ich bin ein deutscher Dichter/ Bekannt im deutschen Land/ Nennt man die besten Namen/ So wird auch der meine gennant"* [*"I'm a German poet/ In Germany well known/ Name the greatest names and/ You're sure to name my own"* Heine & Draper (1982:114)].

References

Bishop, M. G. (1994). The genius of disease. 3. A journey round my skull- Frigyes Karinthy. *Journal of the Royal Society of Medicine*, 87(1), 2-4.

Bradford, R. (2009). *Life writing: Essays on autobiography, biography and literature* edited by Richard Bradford. Basingstoke: Palgrave Macmillan.

Brody, H. (1987). *Stories of sickness*. New Haven: Yale University Press.

Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of health & illness*, 4(2), 167-182. https://doi.org/10.1111/1467-9566.ep11339939

Cantabrana, B., González-Rodríguez, S., & Hidalgo, A. (2016). Una literatura de la enfermedad y la muerte. *Rev Med Cine*, 12(1), 47-59.

Coutts, M. (2014). *The Iceberg: A Memoir*: Atlantic Books.

Derrida, J., & Bennington, G. (2009). *The Beast and the Sovereign*: University of Chicago Press. https://doi.org/10.7208/chicago/9780226144399.001.0001

Frank, A. W. (1995). *The wounded storyteller: Body, illness and ethics* / Arthur W. Frank. Chicago, London: University of Chicago Press. https://doi.org/10.7208/chicago/9780226260037.001.0001

Genette, G. (1980). *Narrative Discourse: An essay in method*. Ithaca: Cornell UP.

Graham, P. W. (1997). Metapathography: Three Unruly Texts. *Literature and Medicine*, 16(1), 70-87. https://doi.org/10.1353/lm.1997.0005

Hawkins, A. (1984). Two pathographies: A study in illness and literature. *The Journal of medicine and philosophy*, 9(3), 231-252. https://doi.org/10.1093/jmp/9.3.231

Hawkins, A. H. (1999a). Pathography: Patient narratives of illness. *The Western journal of medicine*, 171(2), 127-129.

Hawkins, A. H. (1999b). *Reconstructing illness: Studies in pathography* / Anne Hunsaker Hawkins. (2nd ed.). West Lafayette, Ind.: Purdue University Press.

Heine, H., & Draper, H. (1982). *The complete poems of Heinrich Heine: A modern English version* / by Hal Draper. Boston, Mass.: Suhrkamp/Insel; Oxford Distributed by Oxford University Press.

Jurecic, A. (2012). *Illness as narrative*. Pittsburgh series in composition, literacy, and culture. Pittsburgh: University of Pittsburgh Press. https://doi.org/10.2307/j.ctt5hjr8p

Karinthy, F., Sacks, O., & Barker, V. D. (2008). *A Journey Round My Skull*: New York Review Books.

Kleinman, A. (1988). *The illness narratives: Suffering, healing, and the human condition*. New York: Basic Books.

Lejeune, P., & Eakin, P. J. (Eds.) (1988). *On autobiography*. Minneapolis: University of Minnesota Press.

Lubbock, T. (2012). *Until Further Notice, I Am Alive*: Granta Publications.

Preece, J., Finlay, F., & Owen, R. J. (2007). *New German literature: Life-writing and dialogue with the arts* / Julian Preece, Frank Finlay and Ruth J. Owen (eds.). Leeds-Swansea colloquia on contemporary German literature, v. 1. Oxford: Peter Lang.

Rimmon-Kenan, S. (2002). The Story of »I«: Illness and Narrative Identity. *Narrative*, 10(1), 9-27. https://doi.org/10.1353/nar.2002.0006

Schmitt, A. (2017). *The phenomenology of autobiography: Making it real*. Routledge interdisciplinary perspectives on literature, 75. New York: Routledge Taylor & Francis Group. https://doi.org/10.4324/9781315173504

Originalartikel

The Patient as Reader

The uses of intertexts in two Swedish pathographies

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Illness narratives can be said to reclaim the voice of the patient, and while they draw much of their strength from a position of experience and loss, they are also highly mediated and constructed narratives. This article studies, how these textual self-representations are formed in relation to intertexts, and how the authors explicitly use other literary texts and enter into a dialogue with them.

Two pathographies are studied, Anders Paulrud's Fjärilen i min hjärna *("The Butterfly in my Brain", 2008) and Agneta Klingspor's* Stängt pga hälsosjäl *("Closed due to health reasons", 2010, and their specific strategies in incorporating other literary texts: Paulrud through assemblage and community, and Klingspor through resistance and critique, especially of narratives the author feels she is supposed to appreciate. In the end, both authors seem to share a view about literature as potentially helpful and meaningful in conveying experiences and even point to a healing potential in narratives and literature.*

Introduction

"There are other words for this, but they don't belong to me." These words, written by Swedish author Anders Paulrud as he was dying of lung cancer, are his own; the "other words" he refers to are the terminology of the medical world (Paulrud, 2008, p. 13).[1] In his illness narrative *Fjärilen i min hjärna* ("The Butterfly in my Brain", 2008), he seeks to write the story that belongs to him, not to the medical record, positioning himself against the official story and claiming the value of his own perspective. The distance to the medical world, is here established as absolute, but this is not a gesture in anger or resentment; Paulrud is grateful to his doctors and appreciates what they do for him. It is a fundamental delineation of narratives, allowing him to for the rest of the book concentrate on his own story about living with illness and facing death.

The genre of illness narratives – often called pathographies, i. e. autobiographical or biographical narrations about personal experiences of illness, treatment, and sometimes death – are in many ways a reclaiming of voice (Hawkins, 1999, p. 1). Hawkins, who coined the term pathography in its modern form, points out that pathography:

> *"returns the voice of the patient to the world of medicine, a world where that voice is too rarely heard, and it does so in such a way as to assert the phenomenological, the subjective, and the experiential side of illness"* (Hawkins, 1999, p. 12).

In many ways, a medical perspective on life and the body has come to receive a dominant position in our culture and colour the everyday understanding of it (Svenaeus 2013). Pathographies negotiate this, by both incorporating and resisting the medically-dominated narratives that permeate the understanding of illness and health. Jurecic suggests, that modern illness narratives have developed both as acts of resistance to the medical establishment and as a necessary complement to modern medicine:

> *"If one of the consequences of modernity is that we no longer depend upon traditional explanations for suffering, loss, and mortality, and if doctors' offices and hospitals cannot function as spaces where personal meaning can be developed, then the existential questions about human fragility and significance have to be asked and answered elsewhere"* (Jurecic, 2012, p. 10).

The illness narratives have this dual relation to the medical narrative, while at the same time being part of a much longer tradition of writing the self, dealing with life events, disruptions, and the formulation of identity.

While the illness narratives' reclaiming of voice draws much of its strength from a position of experience and loss, they are of course also highly mediated and constructed narratives. In this article, I am interested in how these textual self-representations are formed in relation to intertexts, and how the authors use other literary texts in their narrative. This means, I am primarily discussing explicit intertextual relations, where the authors overtly make use of other texts in the construction of their narrative and enter into dialogue with them. In the end, their use of other works also becomes a suggestion for how their own narratives may be read, and it is possible to see their uses of intertexts as a kind of modelling of a reader-text relationship.

Both my examples are Swedish illness narratives written by already established authors who, in the face of illness, decide to write books where illness forms the centre. Paulrud's already mentioned book is the last he wrote before his death, and here he depicts two illnesses: a brain tumour he is cured from, and lung cancer that will eventually take his life. Agneta Klingspor's *Stängt pga hälsosjäl* ("Closed due to health reasons", 2010)[2] is an account of her life after having been diagnosed with breast cancer; this is an illness she is cured from and she has continued to publish after it. The writers have, in other words, different positions in relation to the fatality of their illness. For both Paulrud and Klingspor, the pathographies are part of a long line of literary works, and their earlier works often contain autobiographical components. This is especially true of Klingspor, whose debut was part of the emergence of the so-called female confessional literature of the 1970s; she has also later continued to use an autobiographical stance in most of her books (Jönsson, 2006).[3] Her oeuvre includes novels, autobiographical accounts, poetry and short stories and bodily, sensuous experiences are often central in them. Paulrud had before his last book written six novels, in many ways circling around themes and details from his own life.[4]

This autobiographical interest, is continued in the illness narratives, although in these, there is not much sign of the playfulness of for example autofiction or postmodern games. Even as these pathographies are crafted with literary intentions and conventions, they align with Couser's point of how illness narratives are often directed towards realism and closure (Couser, 1997; jfr Jurecic, 2012). Both narratives establish an autobiographical contract with the reader, to talk with Lejeune (1989), but at the same time, they distance themselves from a too simple reading of their experiences. Paulrud explicitly calls his book a novel, while the paratexts and the details in the narrative unanimously point towards himself; the narrator is named Anders and has written the same journalistic texts as Paulrud himself has.[5] In an interview, he states he used the label 'novel' to have room also for fictitious parts (Thunberg 2008). Klingspor's essayistic writing is autobiographical, which the paratexts point out, and she also includes photos of herself and her immediate surroundings. At the same time, she creates a distance by writing about herself as "she" and not "I" throughout the book.

There are, thus, distancing gestures in both cases, but the narratives have a high degree of presence and details pointing towards the authors' singular experiences. Jurecic highlights that what illness narratives demand from the reader is a willingness to listen and connect. No matter how literary and even partly semi-fictional the accounts are, they are written from a perspective that asks for connection and for a realisation of a mutual fragility between reader and writer (Jurecic, 2012). Rimmon-Kenan has earlier asked, if illness narratives, because of this, may have something to teach literary criticism (Rimmon-Kenan, 2006), and Jurecic poses the same question: is there something that has disappeared out of view in literary criticism that illness narratives bring to the fore? Building on Sedgwick and Felski, Jurecic suggests, the need for a 'reparative reading', to open up a space for a reading that is theoretically grounded, while at the same time paying attention to things a 'suspicious reading' does not: listening to and acknowledging the realness of the story narrated by a person who tries to communicate, and admitting narrative's possibilities to create a connection between human beings (Jurecic 2012; jfr Sedgwick 2003, Felski 2008). Literature and narratives have as one of their most powerful capabilities the ability to speak to both emotion and cognition, and this is at play in the reading focused on the ill, fragile self.

For both Klingspor and Paulrud, being struck by a severe illness makes them turn away from other exterior things. At first, it is the social world, the community, that even makes the illness truly exist for Klingspor; she has felt a lump in her breast for a while, but not until she tells her friend does it feel real: *"the lump became real through Ylva's reaction, it was created at the moment she said it aloud and exactly as threatening as it perhaps is"* (Klingspor 2010, p. 13–14). But soon, illness primarily comes to mean quitting engagements with the world, and about the world. As she is called into the doctor's office, Klingspor finishes a phone call about a political protest she will no longer be a part of:

> *"Her name is called and she presses the button on the phone, in a second the large world becomes small as a louse and can be crushed between thumb and index finger, on TV a chef beats egg for dessert, her name is called again, the small world calls and she grabs her bag and walks there.*
> *Now, it is the body. Her body. The only one."* (Klingspor, 2010, p. 8)

This image of the world becoming small and then disappearing in her mobile phone is striking, showing us the kind of pause she is facing: where she must put her normal life into brackets, shutting out the outside world, to concentrate on the small, threatened world of her body.

The passage from Paulrud that opened this article, about there being "other words" that do not belong to him, is continued with the line *"From the medical record:"*. After the colon, Paulrud leaves a blank line implying that this other story is not part of his narrative. When he resumes, he speaks of his body and feelings not with the expert language of medicine but with ordinary words; he writes about the pain, the cough, the breathlessness, and a difficulty to swallow that he names *"a curious hesitation when I'm about to swallow."* (Paulrud, 2008, p. 13–14). Even as he is admitted to the hospital, he does not detail too much of the environment; clearly focusing on his own choices in life rather than what life forces him to. The first lines of the book also emphasise the turning away or inward: *"And now I turn downwards, to the birds in the underworld – / Like that, perhaps. If it didn't sound so dramatic. And beautiful."* (Paulrud, 2008, p. 11). Already from the start, then, we see the gesture of turning away, combined with a kind of fascinated reluctance towards the too dramatic, too beautiful, which is something the author struggles with throughout his book.

In both cases, the focus turns towards the small things, the narrators' immediate surroundings – and to their relationship to other literary texts, as these can help them understand and mediate their experiences. In this, the authors take different stances. Klingspor's relation to other texts, is mainly in the form of resistance, even as that resistance, in the end, is broken while Paulrud's strategy is primarily assemblage; using literary texts to create a community of letters where he can be one of the participants.

Paulrud: A community of letters

When Anders Paulrud writes his illness narrative, it is from the perspective of already having given up the hope of a cure. His is a memoir of looking back on life and meeting death. From this perspective, as we have seen, Paulrud turns away from the world at large. In the text, he focuses on only very few people – some of the people that clearly were significant for him in life, like his daughter, are not mentioned in the book except in the dedication. The biggest community he finds is instead with other authors, a literary community of writers that have gone before him and have striking similarities with his situation (cf. Grahams, 1997). The authors in his community seem to be chosen both for their works and for their other affinities with him; good examples here are Lawrence Sterne and Italo Svevo, who wrote books with very similar titles, *A Sentimental Journey* (1768) and *A short sentimental journey* (1949) respectively.[6] Anders brings these books with him as he, marked by illness, travels to Paris. The illness he sees as a second journey, another kind of journey (Paulrud, 2008, p. 65). The metaphor of illness as a journey – highlighted by both Hawkins (1999) and Frank (1995) in their influential analyses of illness narratives – is thus present in both his writing and in the literary company he keeps.[7]

Anders feels an affinity with Svevo's and Sterne's writing as well as with their travelling; he reflects on whether he too is a sentimental traveller, just to conclude that he is probably more of an "ashamed traveller", hiding like a hurt cat (Paulrud, 2008, p. 37). The affinity is equally related to the authors' life and death, and the fact their works were published closely to their own death just as he knows his own will be.[8] In Italo Svevo's case, Paulrud also retells the story of the author's death, when Svevo was refused a last cigarette as he was dying. That is a horrible prospect for a smoker like Paulrud, who has lung cancer from smoking but still cannot quit. He keeps on lighting his cigarettes outside the hospital: *"I quit smoking when* I *quit. Keep up the breathing"* (Paulrud, 2008, p. 128). The smoke he emits is turned into *"a proof that I can still breathe"* (Paulrud, 2008, p. 67).

I want to highlight briefly two especially interesting examples of how Paulrud relates to other literary texts. The first is the way he 'steals' an idea from Joan Didion's *The Year of Magical Thinking* (2005), where she writes about the grief of losing her husband. Paulrud identifies with that grief even as he is mourning himself, not a relative. In his attempts to process his own imminent death, he reads Didion and he is particularly intrigued by the fact that she could not throw away her husband's shoes after his death, as she could not shake the feeling he might need them. This beautiful depiction of how grief can crystallize in small details and in the interaction with things; and this feeling that shoes are more personal than many other clothes and possessions, perhaps especially to a traveller and walker like himself, captivates Anders. He decides to recreate it: *"Exactly like that. I stole the idea from her"*. He polishes his favourite shoes and writes *"To keep"* on their soles (Paulrud, 2008, p. 114). As he uses the idea for himself, the meaning is partly changed, as Paulrud's version includes an imperative to his life partner on how to act. In his relation to the other narrative, he takes an idea and turns it into something tangible an action.

This attempt to take symbols and metaphors and turn them into concrete, tangible things is something that permeates the book. Another example of this aim, is Paulrud's overarching image in the book, the butterfly. This is a metaphor that draws on a cultural history of symbolising the soul, rebirth, transformation, and renewal, but for Paulrud it is a metaphor that is materially present. It comes to mean so much to him because he spots it in the x-ray photo of his brain, where a formation in the middle has the shape of a butterfly; this image is also the cover photo of the book. This carnally present metaphor gives him a way to think about his own life and death, and when he survives the brain tumour, he thinks of it as the butterfly allowing him to fly out into life and the wide world again (Paulrud, 2008, p. 60). As his second illness turns out to be incurable, he imagines the butterfly no longer being able to breathe with its wings, as it is pinned down and dead (Paulrud, 2008, p. 128). One could argue, that the final part of the butterfly symbolism is the book itself, becoming the butterfly that has its origin in his brain and then can fly out into the world, even as its creator has died.

This way of interpreting symbols concretely is also connected to the last author of Paulrud's community I want to highlight here, Lars Gyllensten. Paulrud quotes a passage from him about death, or rather about the time shortly before death. Gyllensten states that a person on the brink of extinction gives away "eager signs of life":

> *"Those signs do not resemble normal speech, as they are sent out when the time is already out, and there is no time left for anyone to answer. They demand neither listener nor like-minded people, but the person who dies is in his own company and talks and sings to himself to convince himself he is still alive, and that this is more important than the fact he is about to die."* (Paulrud, 2008, pp. 71–72; Gyllensten 1963, p. 69)

The speech, carried out by a dying person, is thus a sort of incantation about life, and Paulrud's insistence to write is posed as this kind of chant. This incantation is also, by the materialisation in the form of a printed book, something that will stay. Every time a reader opens the book and reads his words, he is again alive. This is the immortality that literature offers, and that Paulrud searches for as he brings to life the literary fellowship he wishes to join.

Paulrud, thus, is writing retrospectively and on the brink of death, and uses his literary references to build a community and a writer's identity as he contemplates life and loss. Klingspor, who writes in a different mode; throughout her illness, allowing us to follow both the uncertainty of diagnosis and the hope of a cure, instead shies away from literature, resisting what she finds to be too much to handle in her ill state.

Klingspor: Resisting narratives

Agneta Klingspor has, since her debut in 1977, had as a literary project the aim of writing about the body, especially the erotic body. In *Stängt pga hälsosjäl*, she turns to the ill, fragile body and cancer's threat to her life. In this narration, which consists of a textual, chronological story as well as a photographic one. With snapshots of her everyday life, surroundings, and artefacts all taken with her mobile camera, she captures her experience of breast cancer. Notably, even as she creates this narrative, one of its main points is to question and resist the power of narratives, and to some extent theoretical thoughts. As Lenemark points out in an article, Klingspor's story includes most of the recurring components in breast cancer narratives, but her emphasis is different, focusing on the long wait for a diagnosis and the existential questions raised by illness and prospective death. In contrast to the 'normal' account of breast cancer, it is also possible to interpret the ending as more open and unsure than a truly happy end (Lenemark 2018; jfr Couser 1997).

As Klingspor is diagnosed with possible cancer – "it's leaning towards cancer" is the doctor's first turn of phrase – one of her usual ways of dealing with life, reading, is put on hold. In this state of illness where her existence is threatened, she finds she cannot read Susan Sontag. *"No, Sontag is too intellectual for her now. She only wants to know about radiation, chemotherapy, side effects, item by item, the whole process"* (Klingspor 2010, p. 28). Writing her life is still something she can do, and while being an illness narrative, *Stängt pga hälsosjäl* is also in many ways a continuation of long-term work to write her own life in different ways (cf. Jönsson, 2006).

Even if she cannot read Sontag, Klingspor still uses Sontag's famous metaphor of illness as the night-side of life, a citizenship in a parallel kingdom of the sick in a productive way. She is positioning herself as a 'cancerian' with a passport that needs to be stamped: *"she is an enforced citizen, a cancerian, and she has no choice"* (Klingspor 2010, 31). The cancerians, she writes, are mostly invisible, alien but still impossible to discern from others, until they start losing their hair or have a large surgery. Her narrative emphasises distance; when she walks in the city or visits the theatre she feels like a stranger, an outcast compared to the well, as she moves in their world with a lump in her breast.

Klingspor also further elaborates Sontag's imagery of states, as she proclaims her life with illness as an 'undantagstillstånd', i.e. a state of emergency or a state of exception. She even finds herself issuing censorship against death. Death, she writes, is for the well. *"Only the well can speculate, philosophize, mediate over death. The truly ill want to repress death, erase death"* (Klingspor 2010, pp. 32–33). At the baseline of threatening death, speculation is no longer for her. She puts away books that deal too much with death, as well as the sheep skull she usually has placed on her bookshelf. What she primarily turns away from is the mediated death, the death used for shock effect or as part of other people's narratives:

> *"No obituaries, no murders on tv, no violence. The evenings are spent zapping between the channels because men are fighting everywhere on every channel with the fist, the gun, the knife, the rock, the bomb. Where men are, there is blood."* (Klingspor 2010, p. 33)

This critique is not only directed towards other people's stories, but to a high degree also towards herself. A few years before her illness, Klingspor published *Går det åt helvete är jag ändå född* ("If things are going to hell, at least I was born", 2006), a thorough investigation of death, other people's death, often on a large scale, and death in narratives, especially on tv. She even went to a cemetery to study cremation and see the remains of the dead. Now, things have changed. *"You can look death into the eye when you're well,"* she states to her younger, healthy self (Klingspor 2010, p. 34).

As she slowly recovers, the author finds energy to return to texts again, even if she still finds most of them unhelpful. Predominantly, she brings them up to discard them, inhabiting her stance of resistance. She cannot find solace in stories that often seem to help breast cancer patients, like the story about the amazons with one breast surgically removed, the myths about the Greek goddess Hera, or hagiographies. She continues to resist the narratives, especially the ones her surrounding seems to think she 'ought' to find helpful. Fanny Burney, who describes the pain of surgically removing a breast without anaesthesia in 1811 is one of the few stories she wants to think about, as well as women making political protests by baring their breasts (Klingspor, 2010, p. 65).[9] Again, Klingspor does not want the beautiful, the romanticised, or the typical. Her consolation is not in mythical positive figures but in real people's fight in a brutal world.

Finally, when she feels better, she reads Sontag again, even if she mostly disagrees with her. Klingspor's resistance to taking over other people's narratives remains. The disagreement is mainly in her interest in the concrete and tangible; she does not care so much about metaphors as she does about the actual illness experience and therapy. At the same time, she also defends the war metaphors, that are often criticised as limiting to patients, giving them a different spin – imagining herself gathering a liberation army, drawing on her own strengths.[10]

An interesting part of Klingspor's narrative, is the depiction of her alienation towards her own body. Despite its deeply personal stance, the narrative is written in third person, and moreover, she repeatedly refers to herself as "she and the breast". The breast thus takes on an identity of its own – they go to places together, watch things together. She is also seized by tenderness for the breast and addresses it; it seems to both be part of her and not, treated rather like a pet or a friend that she needs to look after. The distance she uses is thus twofold, talking about herself as "she", and then also "she and the breast", and it is part of the depiction of illness as something foreign to the self. Lenemark suggests, this is part of the attempt to narrate what is, fundamentally, unnarratable (Lenemark 2018).

This peculiar distancing comes to the foreground even more, in contrast to a passage, that does not have this separation of the self but where the breast is felt like a part of her. Over two pages, Klingspor writes the history of her breast, depicting it as a living, sensual, and sexually active body part, not a site for cancer (Klingspor 2010, pp. 54–55). This inserted story, written as she is "seized by tenderness towards her ill breast", highlights the special complication of the cancer claiming the breast, of all body parts, and this seems to be part of why the separating out of the breast is so important to her. She never reaches that former wholeness again during this narration, that ends shortly after her recovery.[11]

When, at the end of the book, Klingspor finally finds a narrative she is not resisting, but that she can rest in and be restored by, it is "she and the breast" who are reading, together. Her narrative of choice is Lars Norén's diaries (2008), where the Swedish playwright over almost 1700 pages, retells in detail events and thoughts from his everyday life, noting everything from small purchases, to meetings and disagreements with other people. It is a book, that takes the writing down of everyday life to an extreme. Klingspor reads it in bed every evening, from before the sun sets and long into the night. She feels, she is dragged into the story as if it is a stream and imagines that she is sitting in Norén's armchair: *"She and the breast sit every day in his armchair and wonder what he looks at, if there is a window in front of the armchair and what is outside the window"* (Klingspor, 2010, p. 90).

The diary, and above all the imagined place of reading it, where she can be immersed in another person's life narrative becomes a healing place for the author. The sense of the other text's importance is overwhelming; at the same time, the act of co-creation on the reader's part is highlighted. This is not primarily a text at work, but very much a reader at work with a text. The extent to which her experience is situated in herself and her creative reading of the diary becomes clear when she returns to it later; looking for that armchair again and only finds it in three passages. This still does not take away its influence:

> *"[B]ut it was his armchair that marked her, where he sat thinking or not thinking, just sat because he had to. She and the breast longed for it, that's where she was going to sit still and heal. This unhealed wound, Norén becomes her healing, this despair to not be able to make ends meet, that he must live alone, that he cannot and so forth in eternity, in his rotting body and her rotting and the breast"* (Klingspor, 2010, p. 90).

Together, she and the body-part, that signifies her body's weakness and mortality, are readers that can lose themselves in the "norenian maelstroem" of the diary (Klingspor, 2010, p. 91). Bathing in this current, submerging herself in another person's life narrated in detail, Klingspor finds a connection that allows her to create a restorative community of her own.

Conclusion

In the two illness narratives studied in this article, the authors make extensive use of literature in their writing about their own illness experiences and lives. They strive to write another story than the one provided in medical records and medical terminology, capturing their own individual experiences when facing the biographical disruption of illness. This is an interruption Klingspor sees as a loss of the "ordinary death", a curving of an expected straight line:

> *"to get older and die, a straight line between birth and death, an escalation of time until the body said goodbye in a heart attack or just gave out. Suddenly the straight line curved in 'it's leaning towards cancer."* (Klingspor, 2010, p. 86; cf. Becker, 1997 about disruption and the idea of a predictable life course).

In their attempts to write their illness narratives in contrast to the medical narrative, Klingspor's and Paulrud's relation to literature and intertexts is prominent. I have shown different strategies in their use of other texts in assembling and resisting them. These two opposite strategies and their different uses of literature form an important part of their writing of the self and the disruption of their lives by illness. In the end, Paulrud and Klingspor seem to share a view about literature as potentially helpful and meaningful in conveying experiences, and even point to a healing potential in narratives and literature: Paulrud in finding a kind of meaning pattern in his community of writers, and Klingspor in her immersion in a story about a remarkable person's unremarkable everyday life. This, I would argue, forms a basis to their view of their own writing and what relationship they are envisioning the readers may have to their illness narratives.

In both cases, the authors combine the use of literature with an acute interest in the concrete and tangible, bringing symbols and life-and-death experiences back to the everyday life surrounding them, privileging personal images of life and death over culturally or spiritually established templates. The contrast their narratives are creating is not only with the narratives of the medical world but also with our culture's grand-scale narratives about life and death.

Notes

1 All quotes from the Swedish texts are translated by me.

2 In the title, the word "reasons" (skäl) is misspelt to become one of its homonyms, to instead say "soul" (själ).

3 For more about Klingspor and the confessional literature of the 1970s, see Jönsson, 2006; Sarrimo, 2000.

4 In *Kärleken till Sofia Karlsson* ("The love for Sofia Karlsson", Paulrud, 2005) he even used the real name of the woman he wrote a love story about.

5 To discern between narrator and author, I will refer to the former as 'Anders' throughout the article.

6 The book was written in 1928, just before Svevo's death, and was published posthumously and uncompleted.

7 Hawkins, 1999; Frank, 1995. To what extent Paulrud's story can be seen as a *quest narrative* in Franks's sense is an interesting question. It is possible to see his created community of letters as one of the trophies from his quest. For a more thorough discussion of Svevo, Sterne, and the journey metaphor in relation to Paulrud, see Bernhardsson, 2010.

8 Paulrud died two weeks before his book was published.

9 Klingspor comments, that bared breasts have been used in protests historically, but lately she finds that the breasts have been silent and far from rebellious. This was written before the emergence of Russian punk rock band *Pussy Riot* and their activism. It is also interesting to relate this to how many breast cancer survivors use photos of the naked body and its scars as a protest against body ideals and norms, combining the private and the political in another way. This is true for many individual pathographies as well as a project like *The SCAR project*; for the latter see Ehlers (2015).

10 For more about the war metaphor, see e.g. Sontag (1989), Hawkins (1999).

11 It is worth noting that in her later book with almost the same title as the 2006 book, *Går det åt helvete ska jag ändå dö* ("If things are going to hell, at least I will die" 2016), Klingspor only talks about the cancer in a few passages at the end of the book. In a similar vein as in *Stängt pga hälsosjäl*, she talks about a part of her body as foreign, but this is no longer the breast. Perhaps time has managed to make the breast once again become a natural part of her body. Instead, it is the tattoo in the form of a small, blue dot that is separated from herself. The dot was made at the oncology clinic to help set the radiation correctly. The dot is "everything's centre" and will be there forever. It "*joins her everywhere. The dot is awake even if she is sleeping. […] The dot is her third eye, it has to do with threat of death and hope of life. The dot is, in short, her*" (Klingspor, 2016, p. 110).

References

Becker, G. (1997). *Disrupted Lives. How people create meaning in a chaotic world*. Berkeley and Los Angeles: University of California Press.

Bernhardsson, K. (2010). *Litterära besvär. Skildringar av sjukdom i samtida svensk prosa.* Lund: ellerströms.

Couser, G. T. (1997). *Recovering Bodies. Illness, Disability, and Life Writing*. Madison, University of Wisconsin Press.

Didion, J. (2005). *The Year of Magical Thinking*. New York: Alfred A. Knopf.

Ehlers, N. (2015). The SCAR Project. Disability Aesthetics of Disease, *Journal of Literary & Cultural Disability Studies 9 (3)*, 331-347. https://doi.org/10.3828/jlcds.2015.26

Felski, R. (2008). *Uses of Literature*. Malden, Mass.: Blackwell Publishing. https://doi.org/10.1002/9781444302790

Frank, A. (1995). *The Wounded Storyteller. Body, Illness, and Ethics*. Chicago: The University of Chicago Press. https://doi.org/10.7208/chicago/9780226260037.001.0001

Graham, P. W. (1997). Metapathography. Three unruly texts, *Literature and Medicine, 16 (1)*, 70-87. https://doi.org/10.1353/lm.1997.0005

Gyllensten, L. (1963), *Kains memoarer*. Stockholm: Bonnier.

Hawkins, A. H. (1999). *Reconstructing Illness. Studies in Pathography*. West Lafayette: Purdue University Press.

Jurecic, A. (2012). *Illness as narrative*. Pittsburgh: University of Pittsburgh Press. https://doi.org/10.2307/j.ctt5hjr8p

Jönsson, M. (2006). *Som en byracka. Självbiografi, estetik och politik i Agneta Klingspors författarskap*. Umeå: Bokförlaget h-ström.

Klingspor, A. (2006). *Går det åt helvete är jag ändå född. Verksamhetsberättelse.* Stockholm: Mormor.

Klingspor, A. (2010). *Stängt pga hälsosjäl*. Stockholm: Mormor.

Klingspor, A. (2016). *Går det åt helvete ska jag ändå dö*. Stockholm: Atlas.

Lejeune, Philippe (1989). The Autobiographical Pact. In Paul John Eakin (ed.), *On Autobiography*, transl. Katherine Leary. Minneapolis: University of Minnesota Press.

Lenemark, C (2018). »Det lutar åt cancer«. Agneta Klingspors Stängt pga hälsosjäl och kvinnliga bröstcancerberättelser. In Maria Sjöberg (ed.), *Allvarligt talat* (pp. 299-315). Göteborg: Makadam.

Paulrud, A. (2005). *Kärleken till Sofia Karlsson*. Stockholm: Bonnier.

Paulrud, A. (2008). *Fjärilen i min hjärna*. Stockholm: Bonnier.

Rimmon-Kenan, S. (2006). What can narrative theory learn from illness narratives?, *Literature and Medicine, 25 (2)*, 241-254. https://doi.org/10.1353/lm.2007.0019

Sedgwick, E. K. (2003). *Touching feeling. Affect, pedagogy, performativity*. Durham: Duke University Press. https://doi.org/10.1215/9780822384786

Sarrimo, C. (2000). *När det personliga blev politiskt. 1970-talets kvinnliga bekännelse och självbiografi*. Eslöv: Symposion.

Sontag, S. (1989). *Illness as metaphor, and AIDS and its metaphors*. New York: Picador/Farrar, Straus and Giroux.

Svenaeus, F. (2013). *Homo Patologicus. Medicinska diagnoser i vår tid*. Hägersten: Tankekraft.

Thunberg, K. (2008). »Allt borde upphöra med mig«, *Svenska Dagbladet* January 7.

Originalartikel

Living with illness

Together and alone facing severe illness in four Scandinavian cancer stories

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In this paper, I wish to discuss how people living with severe illness at home depict their lives either in a family setting or alone. Roland Barthes writes in Comment vivre ensemble (1977) about individual life lived in a variety of collective situations in different settings, and calls this idiorrhythmia. One of the settings Barthes studies is the sanatorium, where the figures of Autarky and Clôture, implying living together and living alone, are made relevant. I will use the concept of idiorrhythmia, to discuss ill people living at home either alone or together with relatives. The discussion is based on four contemporary Scandinavian novels: Lars Gustafsson's The Death of a Beekeeper (1978), Ragnar Hovland's A Winter's Journey (2001), Gunnhild Corwin's Ida's Dance (2005) and Ellisiv Stifoss-Hanssen's Let me sleep until this is just a dream (2014). These novels describe young and old adults suffering from cancer, staying at home and the challenges and strategies involved in living together or alone while experiencing severe illness.

According to the French literary critic, Roland Barthes (1915-1980), novels as a genre are particularly fruitful for exploring the manner in which people live alone or together in different social settings. Barthes uses the concept of "idiorrhythmia", originally used to describe individualized monastic life and meaning "following one's own devices" (Talbot, 2005). In *Comment vivre ensemble* (1977), Barthes reflects upon how people living on an island, in a monastery or a sanatorium, balance living together with living alone. At the sanatorium, people live together with other sick people and staff preoccupied with taking care of them. But what is it like being a patient at home, alone or together with people who are both family members and caregivers?

How patients live with others is pivotal, not only with regard to health care services but also as part of a social community. As early as 1943, John Ryle (1889–1950), the first professor of social medicine in England, wrote that it was necessary to study "[...] " (Strøm, 1956:11). Ryle argued, that clinical medicine had evolved into a practice strongly characterized by technique and that the human being, both as an individual and as a member of a family and of social groups, had been forgotten. Ryle's observation from 1943 still remains relevant. As healthcare interventions often take place over short periods of time, the patient's family members form an authority that has become steadily more important. For an ill person, the majority of time is not spent at the hospital, but at home; the patient has more interaction with relatives than with health personnel. Thanks to the almost revolutionary developments in medicine over the last century, patients have on the one hand become dependent on clinicians in order to receive accurate and efficient treatment, but on the other hand spend less and less time in contact with healthcare services. The reduced time spent in a health facility as an outpatient or inpatient has increased the importance of other authorities in patients' everyday lives. This applies particularly to relatives such as partners, spouses, parents and siblings, or friends.

I wish to explore how living with illness, together and/or alone, is depicted in four Scandinavian stories about cancer. Lars Gustafsson's *The Death of a Beekeeper* (1978) tells the story of the cancer-stricken main character Lars Lennart Westin's final six months before his death. He is a divorced teacher who has taken early retirement and lives alone while he is ill, but the book also provides flashbacks to his childhood and his marriage. Ragnar Hovland's *A Winter's Journey* (2001) depicts a couple where the man was diagnosed with stomach cancer in his late fifties, while Gunnhild Corwin's *Ida's Dance* (2006) is a documentary account of 18-year-old Ida, who is suffering from leukaemia. The story covers the six months up to Ida's death, shortly after her 18th birthday. In *Let me sleep until this is just a dream*, Ellisiv Stifoss-Hanssen tells the story of Mia, 26 years old and diagnosed with cervical cancer, and her parents, after the break-up of her relationship with her girlfriend Anne-Marie.[1]

The selected texts reveal two sets of care roles, namely the relationships of the relatives of young adults (<30) and of adults (>40).[2] All the protagonists have hospital appointments but live in their own or their parents′ home and it is these private places of illness I would like to dwell on. The books are different with respect to genre and degree of authenticity, but they all share a focus on the significance of close relatives as the illness progresses and all give less emphasis to the functions of the hospital and the doctor. The novels demonstrate a variety of strategies and challenges connected to the act of living together when a family member experiences serious illness. Here I wish to draw attention to how former social roles as wife, parents and siblings change due to the illness experience. By using David Morris′s ideas of a new patient-family relationship, and Roland Barthes' reflections on living together and living alone in *Comment vivre ensemble* (1977), I will discuss different manners of living together in times of illness.

Living with illness

In 1977 Roland Barthes gave a series of lectures at the College de France, later published as *Comment vivre ensemble*, in which he introduced the word *idiorrhythmia*. The concept describes the processes by which certain monks on Mount Athos in Greece mediate between an idiosyncratic, personal rhythm and the rhythm of the larger monastic communities. Barthes reinvented the religious concept of idiorrhythmia on observing a young mother and her little son:

> *"From my window (December 1, 1976), I see a mother pushing an empty stroller, holding her child by the hand. She walks at her own pace, imperturbably; the child, meanwhile, is being pulled, dragged along, is forced to keep running, like an animal, or one of Sade's victims being whipped. She walks at her own pace, unaware of the fact that her son's rhythm is different."* (Barthes, 2012:9)

The concept is used to shed light on individual life lived in a variety of collective situations placed in different settings. The settings were taken from different novels, such as the island in Defoe′s *Robinson Crusoe* (1718), the private prison cell in Andre Gide's *La Séquestrée De Poitiers* (1930) and the sanatorium in Thomas Mann's *The Magic Mountain* (1924).

In reading *The Magic Mountain*, Barthes notes how the rhythm of the sanatorium differs from that of the outside world: *"Once the structure (the Living-Together)* *is established, it's everlasting; it runs on and on – like a homeostat. […] For the visitor: repulsion and attraction*" (Barthes, 2012:37). This contrasting set of feelings may be detected in some of the characteristics of the sanatorium itself. The place is a mixture of seclusion and social life, of living together and living alone in the presence of death. Barthes primarily discusses the sanatorium in *The Magic Mountain* as a place of "*very strong investment in human relationships and yet all in a context, against a background, of illness and death*" (Knight, 2008:51). He particularly writes about the sanatorium in connection with the figure of 'Cause', but he also reflects upon it with regard to the figure of 'Autarky': "*What is the fascination of the small group, the gang of the sanatorium? Well, I think it´s precisely the state of autarky: see the Greek term autarkeia: self-sufficiency, contentedness, plenitude*" (Barthes 2012:36). The patients at the sanatorium are living in a secluded yet self-sufficient world, feeling safe in the repetitive rhythm of daily life – a rhythm that is individual yet somehow also corresponds to the rhythm of the sanatorium as a collective.

The idea of the sanatorium as an extremely intense social setting was not new to Barthes. It was launched in 1947 in the essay *Sketch of a Sanatorium Society*, in which he states: "*The malaise of not being social is exhausted through social exercises recreated in the image of those from which one has just been excluded*" (Barthes, 2018:64). Interestingly for our discussion, Barthes compares the sanatorium to a family: "*Sanatoriums can be great families, no doubt about it. But if one is obliged to spend time there, must he be complicit in such a cheerful familiarization with disease?*" (Barthes, 2018:67). Whereas Barthes initially stresses the social aspect of sanatorium life, he then modifies and nuances this by including the figure of Clôture in *Comment vivre ensemble*. The word clôture means enclosure, a limited space: "*Enclosure=defines a territory, and by extension the identity of its occupants*" (Barthes, 2012:58). At the sanatorium, the patients adjust to one another by means of the strict routines at the institution but are at the same time able to realize their own solemn pace. In Barthes´ own ending in the *Comment vivre ensemble* seminar, namely the lecture based on Xéniteia, he includes the Compline, the last service of the day in the monastery, as an ideal place of living together:

> "*The idea of compline: beautiful. The community prepares to brave the night (imagine a countryside far away from anywhere, with no lights, so where nightfall really means the threat of darkness). Living-Together: perhaps simply a way of confronting the sadness of the night together. Being among strangers is inevitable, necessary even, except when night falls.*" (Barthes, 2012:129)

Barthes´ formulation is intriguing seen from the perspective of living with severe illness. Facing death, like all the protagonists in our four novels, is facing darkness, feeling that night is falling. Being together in this hour of the day or in this period of life, as in severe illness brings forth the need of both living together and living alone. Turning to *The Magic Mountain* as Barthes does, Diane Knight in a dense and thought-provoking article explores the relationship between Autarky and Clôture as it is dwelled upon in *Comment vivre ensemble, Esquisse d'une société sanatoriale*, as well as in Barthes´s more biographical writings. Here Barthes introduces the regular and obligatory resting on the balcony of the sanatorium as a way of practising the Compline. The Compline and the balcony resting show the combination of autarky and enclosure within the self-sufficient institution scenery: "*The balcony is an extension – at once metonym and metaphor – of the solitary chamber in which Hans will spend seven years of his life*" (Knight, 2008:58). To have access to such a dwelling place as a sanatorium balcony, being wrapped up in blankets as a sign of autonomy, borders and yet freedom and at the same time belonging to the sanatorium with its family-like organization is suggested as the perfect idiorrhythmic way of living.

Barthes´ style has been called "eccentric and obscure" and though he is much read, his methodology is not always easily applicable. The concept of idiorrhythmia, however, has grown popular due to its resilience and the diverse well-known novels Barthes alludes to: "*Barthes´s eclectic choice of primary texts […] offers a model for how researchers might explore idiorrhythmia through the work of other creative writers and literary authors, and across a range of genres and media*" (Harrow, 2015:21). Not surprisingly, then, idiorrhythmia is applied in a variety of fields; such as literary theory, biographical letter writing, pedagogy and philosophy (Knight, 2008; Harrow, 2015; O´Meara, 2012; Stan, 2014).[3] I will transport the concept into yet another discipline, namely medical humanities, using it as a means to reflect upon being a patient in one's family home, living together and/or living alone in the presence of severe illness.

Young adults living at home

In *Ida's Dance*, Ida is still breaking away from her parents when, as an 18-year-old, she is diagnosed with leukaemia. She still lives at home but, via her somewhat older boyfriend, Jonas, and busy social life, she has begun to find her bearings away from home and her parents. Yet the disease draws her back to her family. In particular, her relationship to her mother, the narrator, Gunnhild, is portrayed as extremely close, almost symbiotic, and the bond between the two grows throughout the period of illness. The rest of the family also emerge as very intimate carers. Ida and her disease become a family matter as they exchange different tasks in relation to her: mother drops her off and picks her up, big sister prepares meals, big brother brings high spirits, a little new-born niece provides a will to live on, and father contributes towards the family's strong finances. *Ida's Dance* paints a picture of a family idyll and, within a socioeconomically resourceful context, Ida's illness is treated in an exemplary way. One challenge, however, is how to combine the ill person's need for private life with her family's desire to help and support her. In *Ida's Dance*, Ida's position on the bridge between childhood and adulthood is portrayed as demanding for her mother in relation to Ida's romance with her boyfriend Jonas. The mother's challenges in letting Ida be independent and live a normal life are a factor that in-depth interviews with young cancer sufferers also reveal:

> "*This tension between parents 'letting go' and young people feeling 'overprotected' was apparent in many of the responses from both studies and serves to illustrate one of the triggers that resulted in challenging family dynamics and which served to exacerbate an already difficult set of circumstances.*" (Grinyer, 2009:207)

Gunnhild dislikes Jonas, both because he is older than Ida and because he is accelerating her approach to adulthood. He is referred to as a "scumbag", an extremely negative description given the book's otherwise subdued style and register. The mother provides a candid account of how difficult she finds it to relate to Ida's sex life, and she gives an equally honest portrayal of her jealousy towards Jonas. Ida, however, insists on being with Jonas and her mother grants her wish, eventually accepting the fact that the two young adults will be spending time together. In a scene near the end of the book when Ida is very ill, her mother describes driving Ida to Jonas' flat so that she can spend the night with him. The scene illustrates how the mother recognizes that Ida is not only a child with a need for familial care but also a grown adult with a need for intimacy that her family cannot provide. The novel describes how Ida´s need for belonging to the family and claiming her own individuality is taken care of. At the end of her life the family rearranges the furniture so that Ida can rest in the living room in the daytime. However, Ida dies in her own bedroom, in her own bed, tucked up in blankets, with her nearest and dearest around her. The scene has a subtle resemblance to the balcony setting in *The Magic Mountain*, indicating both a belonging to the group and a place of one's own. Both the mother and the other family members can be said to adjust to Ida's pace, corresponding to the needs of their very ill daughter and sister. Keeping in mind Barthes' reference to the Compline, the monastery bedtime or after-supper prayer, where the monks gather after a day in solitude, Ida's death is rendered as the final coming together before night falls.

In *Let me sleep until this is just a dream* we encounter Mia Jonson, 26 years old, a student of literary science who discovers a large tumour in her cervix at a routine check-up with her gynaecologist. As she is single, Mia's closest caregivers are her parents. Throughout her illness, Mia is transported back to the role of a child as she needs help and care: "*They're in the flat all the time. They get up when I get up, sit down when I sit down, holding out their hands as I cross the floor as if they are standing beneath a nest when an egg is falling. They don't understand what is going on*" (Stifoss-Hanssen, 2014:115). Her parents' desire to provide emotional and practical support illustrates a need recognized in sociological research (Benkel and Molander, 2017:2). Mia's relationship to her parents' caregiving role is ambivalent. On the one hand, she fears being alone and her parents' presence distracts her in a positive way: "*When I'm alone I can feel something spreading within me, grabbing hold of the lymph nodes and squeezing hard. When Mum and Dad are here, I'm just tired*" (Stifoss-Hanssen, 2014:119, 120). On the other hand, she worries about her parents' reaction to the illness and she is sensitive to any sign that it is also difficult for them. In contrast to the caregiving roles in Ida's Dance, which appear much better defined because Ida is so young, Mia finds herself at the cut-off point where it is not as natural for her parents to be her most intimate relations. Many 26-year-olds would have a partner; some would also have children.

The fact that her parents only have a substitute role as caregivers becomes defined when Mia realizes clearly that her former girlfriend Anne-Marie should be the one performing the role. The qualities of this secondary role do not naturally fit in with the role of a romantic partner. Mia's previous girlfriend, Kristin, did not fulfil such a role; on the contrary, she is instead compared to the cancerous tumour itself: "*It was her the gynaecologist had seen in there, her forehead and a single eye. She had taken hold, grown over the canal like a deformed head*" (Stifoss-Hanssen, 2014:136). The most effective care is actually her father's; Anne-Marie's attempts of comfort and care and enhanced communication are thought of in a similar way to those of the neighbouring homosexual couple Rolf and Aksel. Their common feature is, that they afford Mia the opportunity to find time to formulate her own thoughts, as well as to employ humour in an attempt to normalize the situation. Rolf, a practitioner of alternative medicine, gets Mia to open up about how she is feeling. He also puts into words something that is completely central to the novel: *"'It wouldn't hurt to talk a bit more,' he said without smiling"* (Stifoss-Hanssen, 2014:147). Communication is key in *Let me sleep until this is just a dream*, in terms of love, the work of a writer, and disease. The illness unleashes Mia's communicative potential. Her writer's block deserts her and she manages to elucidate her relationship to both Kristin and Anne-Marie. The novel´s coming into being can easily be interpreted as a meta-comment on this (Synnes and Bondevik, 2018:171). This novel is, however, still by far the most upsetting one because the lack of idiorrhythmia between Mia and her caregivers due to the illness experience only seems to be an intensification of a more general idiorrhythmia characterizing Mia´s life as an adult. The non-rhythmic pattern of Mia´s life before she got cancer continues when she becomes ill and makes her particularly vulnerable.

Adults living alone and together

Living with illness can also mean living alone. The main character in Lars Gustafsson's novel *The Death of a Beekeeper* (1978), the 40-year-old teacher and early retiree Lars Lennart Westin, lives a voluntarily isolated existence following a divorce some years previously. He recounts how his children visit him in the summer holidays, but, as the disease worsens, he withdraws more and more from social settings. The portrayal recalls a biological observation from nature, where it is said that bees withdraw from the pack in order to perish alone. Lars does not withdraw from people when he falls ill, but in light of the illness, he intensifies his isolated existence. His withdrawal from society peaks as he burns the letter from the hospital telling him whether he is ill or not, thereby cutting off all communication with the medical staff.

The burning of the letter from his doctor, in which his diagnosis is presumably stated, is perhaps the most crucial scene of the novel. His desire to remain ignorant is a part of what David Morris calls "*[a]n erotics of not-knowing*" (Morris, 2017:96). The entire development of Western medicine is based on the acquisition of new knowledge and an attitude like that of Lars Lennart Westin appears counterproductive. The novel introduces alternative ways of confronting disease. It begins with a description of his dog not wanting to follow him and Westin suspects that it does not recognize his smell. He, therefore, suspects that his smell has changed because of the disease (Regenbogen et al., 2017). However, a conscious neglect is also an option in facing illness:

> *"Not knowing in medicine and in illness is, of course, never a steady state. It exists, as if in counterpoint, only in relation to the knowledge that it interrupts, as knowing and not-knowing alternate, collaborate, interpenetrate, or overlap in what is always an improvisation."* (Morris, 2017:96)

If knowledge may slow down or get rid of the disease, it seems obvious that it ought to be acquired. However, if the condition is chronic or terminal it is not necessarily the case that knowledge will improve either life quality or the physiological condition. The desire not to know cannot only be said to be erotic in the word's original meaning; it is also exotic: it is an act that seems strange to the modern disease mentality of Anglo-American and West European cultures. By burning the letter, the protagonist in Gustafsson's novel prevents the medical gaze from entering his life, or to use Barthes' concept, prevents the experience of possible idiorrhythmia. As the letter is burnt, and he reduces his visits to the doctor to a minimum, the exploration of this challenging adjustment to different rhythms is fully realized.

Physical suffering and pain is an important theme in *The Death of a Beekeeper*. Even when Lars eventually begins to experience strong pains, he chooses not to seek help. Pain has several functions in his narrative: "*It is through pain he experiences that he is a body, amongst other things*" (Haugen, 2002). Lars experiences his body as from a distance making it stand out as an object of its own, which is a common way of responding to disease in the illness literature.[4] The bodily pain asks for a response from him and forces him to communicate and thereby offers a kind of bodily companionship. Pain is, therefore, not only described as negative. Eroticism and pain are linked in The Death of a Beekeeper, and orgasm is portrayed in a way that recalls the descriptions of pain: "incandescent, intense" (Gustafsson, 1978:149). He writes about "[...] *the troublesome similarity between pain and desire*" (ibid.) and takes note of the erotic excitement that returns when, for a while, the pain subsides. The description of pain as bodily awakening is crucial because it signals harmony and rhythmicity within the protagonist himself. The inclusion portrayed in the novel is somehow balanced by the complex yet balanced feelings, both emotional and physical, of the person. Though he is actually living alone, his heightened and intensified bodily experience, in both pain and lust, provides a feeling of togetherness and completion of himself as a subject.

Ragnar Hovland's *A Winter's Journey* consists of two narratives, namely a diary novel and a fictional narrative, both written by a first-person narrator with limited access to the thought and feelings of the other characters.[5] The main character in the diary narrative is an author and amateur musician recently diagnosed with bowel cancer. He lives a busy social life and has been in a close relationship with his live-in partner, T., for many years. The narrator writes about his and T.'s free lives as artists, filled with travel, music, films, talks and visits to restaurants. The encounter with the health services, with their forms, fixed appointments, reports, technical language and an expedient, professional approach to patients, represents the opposite of their lives as artists.

The diary novel in *A Winter's Journey* runs from 29 April, the day after the narrator is told that he has a tumour, to 31 December of the same year, after he has been operated upon and is declared healthy again. The narrator's plan is to carry on living as before, or, as he writes in the first diary entry: "*I'm going to try to live as normally as possible. Do nice things. Listen to good music and watch great films. Move. Eat delicious food*" (Hovland, 2001:9). This recalls Arthur Frank's fourth category of sickness plots, namely, "illness as normality" in which the patient is to live, to greatest degree possible, mentally unaffected by the disease (Frank, 2010). The partner, T., is completely central to the author's existence, both in illness and in health. T. is the first to be told of the cancer diagnosis and they "*agree to keep the good times rolling*" (Hovland, 2001:9). When the narrator worries about the serious side effects of the treatment he is about to receive, he breaks down before he calls T., who is travelling: "I've spoken to T., and it's something of a comfort to speak to her. She is a blessing. She told me about someone who has lived like this for years, who does mountain climbing and all sorts of sporty activities" (Hovland, 2001:40). T. responds to the protagonist´s news in the best possible way, comforting him and giving him hope. She adjusts to his life as a patient by doing what he wants, namely to act normally.

In the fictional part of the book, the main character is Lindemann, an itinerant preacher who has lost his faith. He hitches a ride with a childhood friend, and with a neighbour, Liv, they drive off to find his childhood sweetheart, Johanna. Synnes and Bondevik have read the fictional part as "[...] *a mythologizing of the affliction of cancer and the situation of the diary writer*" (Synnes and Bondevik, 2018:169). I would argue, that the fictional part can be read as an intensification of the diary part's accentuation of a positive social context in dealing with illness. Gaute Sortland makes a similar point, when he refers to the significance of music to both the diary's 'I' and to Lindemann as having a vital social function (Sortland, 2007:47).

Lindemann's trip is motivated by his desire to meet his childhood sweetheart again. The meeting with her does not turn out as he imagined it would, but on his way he is introduced to a number of social relationships that seem to be positive, meaningful and straightforward, representing something important missing in his life so far. Lindemann's poor health and loneliness is compensated for by these meetings, and reflects the "I" in the desire in the diary part to live normally and in close social interaction in the midst of a difficult stage in life. In this way, the importance of living together in the shadow of illness is accentuated.

Final remarks

Living with illness can both mean living alone or living together. As Barthes so poignantly has shown, life in a sanatorium means not only being part of a tight, yet broad and homogenous society, but also being in a state of loneliness, if not actually alone. The same could be said about being ill at home. The majority of patients today are not alone but surrounded by family or friends. Today, caregiving relatives put in as many hours of work as health workers (Holmøy et al., 2014). Developmental trends point towards increasing use of private health care and a broader use of the family (Jenhaug, 2018:45). The American author and literature professor David Morris has with his book *Eros and Illness* (2017) contributed an important humanistic angle to the role of the relative, by showing how relatives are not only present as a vital aspect of the private experience of illness but also how what he calls *eros* enters the institutional aspect of being ill. Eros implies not merely the erotic, but everything that lies beyond reason and is thus diametrically opposed to medicine. Medicine is logos, but within it, eros is also to be found: "*Desire, legitimized as medical eros, offers a power that can help make the passage through illness far less onerous, a power that offers a more truly 'personalized' medicine than genetic profiles alone can promise*" (Morris, 2017:17).

Medical eros is present in all four books discussed here. It is most basically manifested as the undisputed love from partners and parents. But also the representation of pain and eros in *Death of a Beekeeper* brings forth a bodily sensation, giving the cancer-stricken protagonist a feeling of belonging that illustrates medical eros. *Death of a Beekeeper* is fascinating in its insistence on solitude. Lars is portrayed as living in a monastery, due to his routines, his restricted daily life and his asexual behaviour. He refuses to adjust to the rhythm of the medical community or to family and friends. Instead, he experiences his sick body in an intensely, distanced manner and when experiencing pain or achieving orgasm he feels the idiorrhythmia of both living together and alone. In facing illness and pain he meets his Compline. In Hovland´s *A Winter´s Journey* this combination is realized literally, since the relationship of the patient-narrator and his female partner is characterized by flexibility, intimacy and freedom. They travel explicitly together, and alone, and the daily life of the protagonist is coloured by both the presence and distance of his beloved partner 'T'. They adjust to each other in a seamless manner and represent a good example of Barthes' preferred combination of living together and living alone.

A 2017 study raises the point that "[f]*urther research is required on this rarely investigated subject of having an adult child with a severe disease*" (Benkel and Molander, 2017:1). The study of biographical and fictional texts such as *Ida's Dance* and *Let me sleep until this is just a dream* is one way of investigating this aspect. The harmony of *Ida´s Dance* can be seen because the narrator-mother and the rest of Ida´s family adjust neatly to the rhythm of the incurably ill Ida. Ida is the youngest sibling in the family, she is still living at home when she falls ill and the manner her family adjusts to her may be quite similar to how she was treated before her illness. The story of Mia in *Let me sleep until this is just a dream* is the most disintegrated one. Mia and her parents do not follow the same pace and Mia feels alienated both when her parents move into her flat as well as when she returns to her childhood home. Both Ida and Mia have their parents as their most intimate caregivers; yet having access to their capability to perform the role of carer remains a privileged position. It prevents loneliness and counteracts the practical challenges of suffering alone. Corwin's and Stifoss-Hanssen's texts are thought-provoking because they point towards a reversal of the development process involved in being ill and let parents step into the role of caregiver. They demonstrate how *eros* is present, understood both as erotic and as care and support. Medical eros is a necessary part of being ill, whether in contact with health personnel, parents, children, spouse, friends or neighbours. In other cases, as we have seen, a decision against a social dimension leads to an intensification of one's own physical presence.

The reading of texts that discuss the role of care recipient both with and without parents being actively involved demonstrates the need for flexibility in health care. This also includes a reminder of the historical changes that have taken place. Roland Barthes wrote in 1947 from his own experience of being a sanatorium patient about the sole benefits of being transported back to childhood:

> *"Paternalist, feudal, or liberal, bourgeois sanatorium society, through various pretences, always tends to revert to the irresponsibility of childhood. It is an essentially puerile society, corresponding in its various facets to the bourgeois image of childhood. We know that for most French writers over the last century nothing is as perfect, nothing is as happy, as childhood and there is no human mission more vital than recovering it."* (Barthes, 2018:67)

However, the study of our four contemporary texts on being ill reveals that childhood is not necessarily the preferred setting. For Mia it is highly problematic, and none of the adults in Gustafsson and Hovland's novels indicate any longing to revert to childhood. Rather, they seem to find strength and appreciation in their in-dependency and control over the illness experience. Ida in *Ida's Dance* is the youngest patient, almost a child, and seemingly content. Yet the story narrated by her mother leaves some uncertainty as to what Ida as a patient really means. It is only direct speech from Ida that is rendered. All in all, an awareness of the need for a flexible and subjective approach towards the social setting of being a patient is one general, yet crucial, lesson learned from reading these illness stories.

The four books show that despite the love surrounding the patients, the pace and rhythm of the lives of the ill people and the healthy people are different. Susan Sontag, who was a friend and admirer of Roland Barthes, is known for her opening paragraph in *Illness as Metaphor*:

> *"Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place."*

Beginning a book as Sontag does, advocating the need for a concrete, medical language of illness and illness experience by using metaphors, naturally stresses the importance of the statement. The rhythm of these two kingdoms is unlikely to be identical. The rhythms, to use Barthes' vocabulary, can be related or they may differ as illness interferes with daily life. The roles of the patient and the relatives are influenced by the diminished state of health, which is reflected in the idiorrhythmia of the stories being told. The question, then, is more one of whether the ill and the healthy people are able to adjust to one another.

Finally, Roland Barthes discusses idiorrhythmia in connection with illness, describing the exemplary setting of the sanatorium. The reference to the sanatorium where the patients both follow the daily rituals of the institution and their own individual pace brings together the living together and the living alone. Whereas fulfilling this idiorrhythmic ideal may be challenging no matter what life situation one is in, experiencing illness clearly places the patient and his or her family in a particularly demanding and vulnerable situation. Family and friends have a great burden of responsibility to adjust to the pace of the ill people. Yet, as shown by both Barthes and *Ida´s Dance*, tucking someone in, giving them a room of their own and yet offering company and comfort is one possible and achievable way of practising the difficult exercise of both living together and living alone in the presence of severe illness.

Notes

1 The works by Hovland, Corwin and Stifoss-Hanssen are based on personal experiences of sickness, although only Corwin's is purely biographical. In terms of genre, the books by Gustafsson, Hovland and Stifoss-Hanssen are classed as novels.

2 In *Living Conditions Survey on Health 2015*, Statistics Norway uses the following age groups: 16–24 years, 25–44 years, 45–66 years, and 67 years and above. My source material represents the first three groups. Young adults are defined as people aged 18-29 (Bleyer et al, 2017:569).

3 For a full exploration of the inter-disciplinary potential of idiorrhythmia, see Stene-Johansen, K., Refsum, C., & Schimanski, J. *Living Together - Roland Barthes, the Individual and the Community* (2018).

4 See for instance Agneta Klingspor´s *Stängt pga hälsosjel* [Closed due to health concerns] (2010), an autobiographical narrative (pathography) on breast cancer. The narrator treats the cancerous breast as both a part of herself and as an object in itself. Many thanks to Katarina Bernhardsson for making me aware of this expression of bodily dualism.

5 The two parts are marked differently. The titles of the diary novel's short chapters are in the form of dates of events (e.g. "9.5") with the text in italics, while the fictional chapters are numbered and the text not italicized.

References

Benkel, I., & Molander, U. (2017). A qualitative study of the experiences of parents with an adult child who has a severe disease. *INQUIRY: The Journal of Health Care Organization, Provision, and Financing, 54*, 1-6. https://doi.org/10.1177/0046958017727107

Barthes, R. (2012). *How to live together: Novelistic simulations of some everyday spaces*. (K. Briggs, Trans.). New York, NY: Columbia University Press.

Barthes, R., & Gladding, J. (2018). *Album. Unpublished correspondence and texts.* New York, NY: Columbia University Press. https://doi.org/10.7312/bart17986

Bleyer, A. et al. (2017). *Cancer in adolescents and young adults* (2nd ed.). Cham, Switzerland: Springer. https://doi.org/10.1007/978-3-319-33679-4

Bondevik, H., & Stene-Johansen, K. (2011). *Sykdom som litteratur. 13 utvalgte diagnoser.* Oslo: Unipub.

Corwin, G. (2006). *Idas dans*. Oslo: Bokklubben.

Frank, A. (2010). *Letting stories breathe. A socio-narratology*. Chicago, Ill: University of Chicago Press. https://doi.org/10.7208/chicago/9780226260143.001.0001

Grinyer, A. (2007). *Young people living with cancer. Implications for policy and practice.* Maidenhead, UK: McGraw-Hill/Open University Press.

Gustafsson, L., & Qvale, P. (1978). *En birøkters død*. Roman. Oslo: Gyldendal.

Harrow, S. (2015). Living alone together: Barthes, Zola, and the work of letters. *L'Esprit Créateur, 55(4)*, 21-38. https://doi.org/10.1353/esp.2015.0054

Haugen, I. G. (2002). *Som om en flytande metall eller något sådant hade trasslat in sig i muskulaturen. Smerte som litterær utfordring i Lars Gustafssons En biodlares död* (MA thesis). University of Oslo.

Holmøy, E. Kjelvik, J., & Strøm, B. (2014). Behovet for arbeidskraft i helse- og omsorgssektoren fremover. *Rapport nr. 14*. Oslo: Statistics Norway.

Hovland, R. (2001). *Ei vinterreise*. Roman. Oslo: Samlaget.

Jenhaug, L. M. (2018). Myndighetenes forventninger til pårørende som samprodusenter i omsorgstjenester. *Tidsskrift for velferdsforskning [electronic resource], 21(1)*, 39-58. https://doi.org/10.18261/issn.2464-3076-2018-01-03

Knight, D. (2008). 'Except when night falls': Together and alone in Barthes's Comment vivre ensemble. P*aragraph, 31(1)*, 50-60. https://doi.org/10.3366/E0264833408000060

Moseng, O. G. (2003). *Ansvaret for undersåttenes helse 1603-1850*. Oslo: Universitetsforlaget.

Morris, D. B. (2017). *Eros and Illness*. Cambridge, MA: Harvard University Press. https://doi.org/10.4159/9780674977914

O'Meara, L., (2012). *Roland Barthes at the Collège de France*, Liverpool, UK: Liverpool University Press.

Regenbogen, C., Axelsson, J., Lasselin, J., Porada, D., et al. (2017). Multisensory detection of sickness. *Chemical Senses, 42(2*), E47-E48.

Sortland, G. M. (2007). *»Det er ting eg vil vise deg. Fine ting« : melankoli og trøyst i Ragnar Hovlands roman Ei vinterreise* (MA thesis). University of Oslo.

Sovik, O. (2001). Sykdomsbegrepet i historisk og dagsaktuell sammenheng. *Tidsskrift for Den norske legeforening, 121(22)*, 2624-2627.

Stan, C., (2014). A sociality of distances: Roland Barthes and Iris Murdoch on how to live with others. *Modern Language Notes, 129(5*), 1170-1198. https://doi.org/10.1353/mln.2014.0099

Stene-Johansen, K. (2013). Legers plikt til å lyve. *Tidsskrift for Den norske legeforening, 133(23-24)*, 2580. https://doi.org/10.4045/tidsskr.13.1468

Stene-Johansen, K., Refsum, C. & Schimanski, J. (Eds.). (2016). *Å leve sammen: Roland Barthes, individet og fellesskapet*, Oslo: Scandinavian Academic Press.

Stene-Johansen, K., Refsum, C., & Schimanski, J. (Eds.). (2018). *Living Together - Roland Barthes, the Individual and the Community*. Bielefeld, Germany: Transcript Verlag. https://doi.org/10.14361/9783839444313

Stifoss-Hanssen, E. (2014). *La meg sove til dette bare er en drøm*. Bergen: Vigmostad & Bjørke.

Strøm, A. (1968). *Lærebok i sosialmedisin* (3rd ed.). Oslo: Fabritius.

Synnes, O., & Bondevik, H. (2018). Litterære strategiar og sjølvopplevd kreft. *Norsk litteratur¬vitenskapelig tidsskrift, 21(02)*, 161-182. https://doi.org/10.18261/issn.1504-288X-2018-02-04

Talbot, A-M. (2005). Idiorrhythmic monasticism. In A. P. Kazhdan (Ed.), *The Oxford Dictionary of Byzantium*. Oxford, UK: Oxford University Press. Accessed 13 February 2019 at http://oxfordindex.oup.com/view/10.1093/acref/9780195046526.013.2427.

Wiltshire, J. (2000). Biography, pathography, and the recovery of meaning. *Cambridge Quarterly, 29(4)*, 409-422. https://doi.org/10.1093/camqtly/29.4.409

Originalartikel

Doing Illness

Cancer Narratives in Digital Media

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Through three case studies, the article explores how digital media have been used in recent years to depict and comprehend experiences of cancer. It first investigates the illness blog, specifically Swedish journalist and musician Kristian Gidlund's immensely popular blog In My Body, in which he, from 2011 to 2013, shared the narrative of his struggle with an aggressive, incurable, and ultimately deadly stomach cancer. It continues by discussing Italian engineer, artist, and hacker Salvatore Iaconesi's digital open-source project La Cura – The Cure (2012), which has great relevance from both the digital and the medical humanities perspectives in the way Iaconesi uses his personal narrative of brain cancer to encourage people to join his struggle to find a cure. Finally, it analyzes the American couple Ryan and Amy Green's videogame That Dragon, Cancer (2016). A game differing significantly from video and computer games in general and from other games taking cancer as their subject by letting the player enter the role of caregiver to a small child dying of cancer. Expanding on Lisa Diedrich's theoretical concept of "doing illness", the article emphasizes the performative dimension of narrating illness in digital media, considering how these authors and creators negotiate with narrative, cultural, and medial scripts when portraying their cancer experiences. It highlights the interactive and participatory dimension of doing illness in digital media, by exploring how the blog, open-source project, and videogame *both invite and limit the audience's opportunities to interact and participate with the illness narrative conveyed.*

Introduction

"Illness calls for stories", Arthur Frank (1995) states in his by the now-classic book on illness, *The Wounded Storyteller* (p. 54). Although these words were written at the beginning of the Internet era, they seem especially true today considering the vast number of biographically anchored illness narratives produced, distributed, and consumed via digital media in recent years. From a media perspective, however, research into pathographies and autopathographies – that is, biographical and autobiographical narratives of illness (Couser, 1997; Hawkins, 1999) – has tended to focus more or less on illness narratives conveyed by the medium of the book. As Tamar Tembeck (2017) points out, *"comparatively little research has focused on autopathographic practices beyond the literary world"* (p. 207), even though renowned scholars in the field, such as G. Thomas Couser (2009:13), have acknowledged the impact of digital media when it comes to the worldwide proliferation of illness narratives.

Against this background, the article seeks to broaden our perspective on illness narratives by acknowledging that they come in different forms and are conveyed by different media, a fact Stella Bolaki (2016) captures in the phrase constituting the main title of her book, *Illness as Many Narratives*. From this viewpoint, the conventionally printed book is to be regarded as a medium with its own affordances and constraints when it comes to narrating illness, although this is rarely noted in research. The same is, of course, true when it comes to the material in focus here: an illness blog, an open-source project, and a videogame. In short, the article presents an explorative study of how these specific digital media formats, or genres, are used to narrate the experience of being diagnosed with or living in the shadow of one of our most feared diseases: cancer.

This article begins by considering the illness blog, specifically, Swedish journalist and musician Kristian Gidlund's immensely popular blog *In My Body*, in which he, from 2011 to 2013, shared the narrative of his struggle with an aggressive form of incurable and ultimately deadly stomach cancer. Then I continue by discussing the Italian engineer, artist, and hacker Salvatore Iaconesi's digital open-source project *La Cura – The Cure*, from 2012, a project of great relevance from both the digital and medical humanities perspectives in the way Iaconesi uses the personal narrative of a glioma in his brain to encourage people to be part of his struggle to find a cure. Finally, I consider the video game *That Dragon, Cancer,* released on January 2016. This game differs in significant ways from video and computer games in general and, in particular, from other types of games taking cancer as their subject by letting the player enter the role of caregiver to a small child dying of cancer.

These cases have been selected to exemplify the multifaceted ways digital media are used by people affected by cancer to narrate their experiences. However, the article does not provide an exhaustive account of how digital media are used for this purpose, nor is it the intention. The article does not consider how cancer is narrated in YouTube vlogs (Arduser, 2017; Hale, Gonzales & Richardson, 2018), status updates on Facebook (Stage, 2017), or online communities and networks depicting in more ordinary ways what living with cancer really means (Kennedy, 2016), to mention just a few examples.

From a methodological perspective, the article largely comprises a narrative analysis of the above-mentioned material. The focus is on the story expressed in the examined medial contexts, not least on how digital media both enables and limit a certain kind of storytelling. In this regard, I have been inspired by Lisa Diedrich's (2007) theoretical concept of 'doing illness' by which she emphasizes that narratives of illness involve a performative dimension, not being fixed, but in constant motion. According to her, they entail constant negotiation with narrative, social, and cultural scripts.

In the following, I expand on this idea by considering how the analyzed narratives also negotiate with medial scripts, with a focus on the possibility of the audience interacting with and participating in doing illness. In this, the audience should be understood both as an implied audience, that is, the studied authors and creators do illness in relation to preconceived images of the audience (cf. Schmidt, 2013), and as a concrete audience comprising the actual blog readers, contributors to the open-source project, and video game players. In digital media research, it is often argued that digital media distinguish themselves from analogue media by their potential for interaction and participation. One has talked about digital culture as a 'participatory culture' (Jenkins, 2006), in which audience members leave their passive role and become users, and hence are more active and freer to interact with and participate in relation to the content at hand (Brough, 2014; Bruns, 2008; Lind, 2015, 2012). As is evident in the following case studies, however, the invitation to interact and participate with the content takes different expressions in the blog, open-source project, and video game, as does the actual interaction and participation.

Blogging the cancer experience

Kristian Gidlund launched the blog *In My Body* in March 2011 in reaction to his cancer diagnosis, which he described in the blog's first entry. This fact is itself congruent with the motives underlying most illness blogs on cancer and other life-threatening diseases. In short, these blogs could be regarded as a response to the trauma, or the biographical disruption of the sense of one's former self, caused by the diagnosis (cf. Bury, 1982; Conway, 2007; Diedrich, 2007).

The blog is a digital format often viewed as part of 'Web 2.0'. In short, it could be seen as a 'remediation' (Bolter & Grusin, 1999) of the traditional analogue diary, the main difference being its public nature and the reader's ability to read and directly interact with the personal narrative, more or less in real-time. Due to this fact, the blog has been viewed as particularly authentic, rendering life while it is going on (cf. McNeill, 2003, Rettberg, 2014, Sorapure, 2003).

Consequently, it is easy to understand the blog's appeal to those, like Gidlund, who suddenly face severe illness. On a formal level, Gidlund's blog can be seen as an example of a traditional illness blog. It was published using a pre-existing template provided by the blog-publishing service Blogger and it mainly comprises text entries concerning the experience of illness, occasionally illustrated with photos, which are presented in reverse chronological sequence (cf. Nesby & Salomonsen, 2016:46). While it was up and running, the blog's readers could comment on the entries using the built-in commenting feature.

In one important respect, however, Gidlund's blog distinguishes itself from blogs in general and from other illness blogs in particular, namely regarding the interactive dimension. From the outset, Gidlund insisted on the private nature of his blog in relation to the reader: *"This is a selfish blog. Created by myself. For myself. If you want to read it, you are free to do so. But this is my way of dealing with this situation"* (Gidlund, 2011, my translation). In line with this statement, Gidlund was consistent in not participating in the lively discussions that his blog entries prompted.

The explicit author-reader interactivity often seen as an important dimension of cancer and illness blogs (see Nesby & Salomonsen, 2016; Page, 2012), in which, the blog's function is to establish mutual communication between the ill person and a larger group of readers, is declined in Gidlund's case. Unlike the cancer blogs

Ruth E. Page (2012) investigates, Gidlund does not tell his story *"explicitly with the purpose of connecting with a community of users"* (p. 54), even though he expresses the awareness that he is writing for an audience whose scope he does not initially understand.

The blog's readers seem to have been untroubled by Gidlund's unwillingness to communicate with them in the comment field, or in other ways. On the contrary, many of the blog's readers were from the very beginning eager to interact with the content uploaded. It is also clear, that, their comments expose the emotional involvement that this kind of blogging often evokes. The comments largely consist of greetings to Gidlund and wish for his quick recovery, together with advice on various treatments for cancer.

It is also striking that the more emotionally charged Gidlund's entries are, the more comments they elicit. One of his last entries, for example, in which he declares that his narrative, and soon his life, has come to an end, elicited 1589 comments, compared with only 373 comments for the previous entry. This illustrates, how digital media formats such as blogs and Facebook generally encourage the production of emotionally charged stories to which readers can connect and respond (Garde-Hansen & Gorton, 2013).

Notable in the readers' comments are their strong emotional involvement with Gidlund's story. Many comments describe how, when reading, the commenter was physically moved to the extent that "*tears slowly fill [their] eyes*", for example. In line with the Swedish cancer blogs analyzed by Yvonne Andersson (2007), the readers' emotional involvement with Gidlund's blog could also be exemplified by their sending "*strengthening hugs*" or the like (p. 13). It is evident, that the readers greatly valued the emotional experience of reading the blog, while the social value ascribed to the blog seems high. Gidlund's confession that cancer affected his life in every possible way frequently prompted reader narratives about their own experiences as cancer patients or as relatives or friends of people living with the disease. This illustrates, how the blog, in sharp contrast to Gidlund's statement that it is a 'selfish blog', functioned as a digital platform creating opportunities for his readers to expose their own personal struggles with cancer, making the disease into a collective shared experience.

In this regard, one could compare Gidlund's blog to discussions taking place on internet discussion forums, and especially to what Page (2012) calls 'second stories', i.e. "*stories or story episodes that follow a narrative that has been told either immediately before, or in close proximity to, the turn that has preceded it*" (p. 30). She illustrates, the use of second stories by an episode of one person telling about witnessing an accident, which evokes a similar story from the person listening. The same logic is to be found in Gidlund's blog. It is also evident, that the second stories, in this case, correspond well to the overall function of the second stories that Page highlights: that of being supportive and building solidarity.

In some cases, however, the second stories on Gidlund's blog become what Page (2012) calls "*face-threatening*" by "*adopting an opposing role*" (pp. 39, 41). More precisely, some blog readers dispute the authenticity of the blog and the truthfulness of Gidlund's depiction of his condition, as in the following example, which Gidlund himself cites in the blog: "*No one will miss you when you die. You just write to show how good you are. You are self-conscious. Everything you do is well thought out.*" (Gidlund, 2013a, my translation). In addition to exemplifying the negative side of sharing personal experiences on the Internet, the fact that Gidlund himself chooses to quote from this post shows that he, after all, reads the discussion in the comment field, even though he does not actively participate in it. Nevertheless, such critical comments should be considered exceptions confirming the rule. Most of the blog's readers did appreciate what they saw as Gidlund's authentic depiction of his fight against cancer, and besides the affecting content, they repeatedly emphasized the blog's aesthetic dimension: the fact that Gidlund is an accomplished writer, who succeeds in narrating what might be considered unnarratable. In other words, what makes Gidlund's blog really stand out in the readers' eyes is its artistic expression, which in turn makes it difficult to dismiss it negatively as non-art or so-called 'victim art', a fate encountered by many printed illness narratives in recent decades (cf. Diedrich, 2007; Jurecic, 2012).

The high aesthetic value ascribed to the blog, together with the massive media coverage that soon made Gidlund into a celebrity, probably explains why he was eventually contacted by Forum, one of Sweden's most renowned book publishers and part of the Bonnier media group, offering to publish the blog in book form. The fact that the blog was 'remediated' in this way into, not one but two, traditional printed books (Gidlund, 2013b, 2013c) further distinguish it from regular illness blogs published only in digital form.

The remediation of the blog into book form also illustrates, the affordances and constraints of these two media forms when it comes to representing the cancer experience. A significant medium-specific difference between the blog and the books concerns the interactive and participatory dimensions touched on above. While the blog reader could follow the cancer experience in real-time, as it was happening, the reader of the books read about the events at a safe distance after they had taken place. Like Gidlund himself, the blog's readers did not know where the story would go next, and they could, as one reviewer wrote, *"keep pace with the author, hoping and despairing with him"* (Lindroth, 2013, my translation). The readers of the books, in contrast, take part in a story that has already been completed and moulded into a form that fits the book as a medium. Gone are the exact date indications of when blog entries were originally written; rather, in the books, the passage of time is marked by indications of the then-current month. The profound comments in the comment fields and the links to the music that forms a kind of a soundtrack to the blog are similarly absent. Retrospectively, the narrative conveyed in the book format also acquires a completely different dramaturgy, with a clear beginning, middle, and end, and with clearly marked turning points. The first when Gidlund is told that he is cured, and the second when he shortly thereafter receives notice that his cancer has returned and this time is incurable. As the same reviewer pointed out, this, together with the knowledge of Gidlund's death, leads to a completely different reading experience coloured by *"powerlessness"* (Lindroth, 2013, my translation).

Interestingly, Gidlund himself self-reflexively comments in the blog about how he views these two media formats assigning them different functions. The blog is viewed in terms of therapy, associating it with the role writing often plays when it comes to illness narratives in general and illness blogging in particular (Gubar, 2016). The continuous writing performed in the blog, was a way for Gidlund to act as a writing subject, but also a way for him to communicate with the outside world, with friends and relatives, about what he was going through. The books, on the other hand, constitute a testament, *"[a] monument. My runestone in the fields. The street that bears my name"* (Gidlund, 2013b:329, my translation). This description actualizes a relatively traditional view of the printed book as a medium considered more persistent than the blog, a notion largely dependent on the fact that the book, like the runestone, is a material object. Despite emphasizing the digital blog's positive therapeutic function, it is valued negatively by Gidlund. Due to its immateriality and volatility, the blog, in the long run, lacks the printed book's long-term stability and memory-preserving potential. It is also the publishing of the two books that finally made it possible for Gidlund to transcend the status of an illness blogger and truly become the author that he had dreamt of being for so long. In many ways, it was his cancer that in the end elevated him into an acknowledged writer.

Exposing and crowdsourcing cancer

As in the case of Gidlund, where the blog and the books could be viewed more or less as responses to the existential limbo caused by the cancer diagnosis, Salvatore Iaconesi's project, *La Cura – The Cure*, could be viewed as his attempt to master the fact that he was diagnosed with brain cancer.

La Cura consisted of a website where Iaconesi (2012a) shared his hacked medical records and x-rays of his brain and the extensive social media network that soon accompanied it. The project began in September 2012 when Iaconesi, himself an artist, posted a video on YouTube entitled *"My Open Source Cure"*. After declaring *"I have brain cancer"*, he urged the viewers to participate in curing him:

> *"So what I ask is give me a cure. … Use the data and information and digital images in open format which I published about my head condition … to produce something … to produce a video, a graphic, an artwork, a game, or maybe even to study the information to find a cure for me"* (Iaconesi, 2012b).

This invitation to interact and to participate in this social media project stands in sharp contrast to how Gidlund in his blog self-consciously declined this same possibility. By means of this 'crowdsourcing' gesture, Iaconesi fully embraced the participatory and intercommunicative dimension of digital media. This is accentuated, if one considers Iaconesi's choice of media platform on which to share the narrative of his disease, YouTube, by that time considered to be the largest community-building video sharing site on the internet. At the same time, the fact that Iaconesi's project was based on the audience's willingness to participate underscores that it, strictly speaking, was not Iaconesi himself who was 'doing' illness. Instead, he had a more *cura*torial role as the one who, through sharing his illness narrative, spurred others to expand on it through their narratives and artworks and later curated them.

By hacking into and sharing his medical records openly on the Internet, which he afterwards described as easier said than done due to Italian patient rights legislation (Delfanti & Iaconesi, 2016: 127) Iaconesi actively resisted being objectified and reduced to the figure of 'the patient as text', in the words of Petter Aaslestad (2009). Instead, Iaconesi came to embody the patient-activist of the 'Health 2.0' movement in at least two ways: first, on a personal level, by trying to figure out how he should act vis-à-vis the treatment of his own brain cancer, by reaching out to actors other than the traditional medical authorities and, second, on a more general level, by trying to raise awareness of cancer by not letting himself be defined by the medical gaze alone, widening the notion of what a cure could be. The project could be seen, as a kind of translation between the medical community with its views of cancer, and the notions of cancer flourishing in the culture at large.

La Cura was enormously successful. The website soon went viral and by 2014 Iaconesi had received more than one million responses to his illness narrative in the form of art pieces, audio recordings, stories, films, performances, text messages, and medical advice from all over the world (Delfanti & Iaconesi, 2016:132). Notable among the contributions are, for example graphic designer Alessandro Damin's image of a brain in the style of a classic advertisement for the Italian typewriter and computer manufacturer Olivetti, and artist Patrick Lichty's full-scale 3D sculpture of Iaconesi's brain (cf. Delfanti & Iaconesi, 2016:133; Stage, 2017:107).

La Cura soon developed into an extensive transmedial narrative (Jenkins, 2008) involving different media forms as well as different actors. Medical experts also participated in the project by sharing their advice as to the best medical treatments for Iaconesi's brain tumour. Through the contacts the project established between Iaconesi and brain surgeons from around the world, he finally managed to assemble a medical team that successfully removed the tumour and at least physically cured him of cancer. *La Cura* thus fundamentally differs from Gidlund's blog; while the latter was largely marked by a tragic plot, Iaconesi's project ended happily and can be viewed as having what Couser (1997:39) calls a comic plot or Frank (1995:115) 'a restitution narrative' that ultimately concerns the 'triumph of medicine'.

In light of the project as a whole, *La Cura* can be seen as one of many examples in which doing illness in digital media is used to negotiate the traditional view of the patient as passive (cf. Stage, 2017:106). Iaconesi himself emphasized in interviews throughout his experience that making his disease into an art project allowed him to remain the same amid the chaos of his cancer diagnosis. In other words, he insisted on 'biographical continuity' (Williams, 2000:61) instead of biographical disruption in the face of the disease: "*My personal purpose for this disclosure is to autonomously shape my own human condition. I have a disease but I am not a 'diseased person'. I am a person*" (Iaconesi cited by Lichty, 2012).

In *Networked Cancer* (2017), Carsten Stage uses *La Cura* to exemplify what he sees as a recent trend in narratives of illness, fostered by the development of new digital media. Stage's (2017) main argument in the book is that we are "*currently witnessing the rise of a new type of personal narrative-affective cancer practice on social media, which adds to the existing types of cancer narratives*" (p. 1). More precisely, Stage

(2017) calls this new practice an ‘entrepreneurial cancer practice’ (p. 1) characterized by cancer patients responding to their diagnosis and treatment by making the disease into a project using digital tools and infrastructure, primarily social media such as blogs, Facebook, and Twitter. They use these social media platforms positively, to make things happen, instead of letting themselves be paralyzed and devoured by their disease.

In a way, this entrepreneurial spirit could also be said to characterize Gidlund’s blog. As mentioned above, it is his blogging about his cancer disease that ultimately makes him the author he always wanted to be. At the same time, Gidlund’s blog fundamentally differs from the digital practices that Stage investigates by not explicitly using the personal cancer experience to raise money for cancer research or, as in the case of *La Cura*, to raise awareness of cancer overall. In Gidlund’s case, this is more of a side effect than a stated goal.

Cancer and videogames

The independent video game *That Dragon, Cancer* could be regarded as more in line with Stage’s conception of entrepreneurial cancer practice. Computer programmer Ryan Green created this game together with his wife Amy in response to the death of their five-year-old son Joel, who had been diagnosed with terminal cancer at the age of twelve months. In interviews and talks, and in the documentary *Thank You for Playing* (Osit & Zouhali-Worrall, 2015), they describe creating the game to commemorate Joel and to raise awareness of what it means to care for a deathly ill child. The game’s entrepreneurial spirit is also highlighted by the fact that it was made possible by a Kickstarter crowdfunding campaign. This shows itself in the final version of the game, in which the Greens incorporated in the gameplay the voices of some of their financial supporters, in the form of letters and artworks concerning similar losses of close family or relatives. As in the case of *La Cura*, and to a lesser extent *In My Body*, this illustrates how doing cancer in *That Dragon, Cancer* goes beyond the personal level, opening up a collective dimension of cancer.

At the same time, it is evident that *That Dragon, Cancer* has a biographical anchoring, and as Couser (2017:380) has acknowledged, one could characterize it as a video game memoir. Throughout, the game uses authentic material such as recordings of Ryan and Amy’s voices and of Joel’s giggling, crying, and screaming. The game also ends by showing real pictures of Joel and his family. However, in contrast to the other cases investigated here, *That Dragon, Cancer* does not center on narrating the cancer experience from the inside, from the perspective of the person living with the disease. What the game instead focuses on, is letting the player adopt the caregiver's perspective, although it is possible to occasionally switch roles, and experience the situation through, for example, Joel's eyes or from the perspective of the doctors, as in the scene where the Greens are told that Joel's cancer is incurable. The focus is constantly changing, giving a complex and multi-dimensional narrative about the cancer experience being rendered in the game. In this respect, the affordances of the video game medium could be said to be used to the utmost.

Otherwise, *That Dragon, Cancer* is a highly narrative game with a playing time of approximately two hours. It could be seen as an example of what Astrid Ensslin (2014) calls 'literary videogames', that is, "*digital artefacts that combine so-called ludic (from Latin* ludus*: game or play), and literary (from Latin* littera*: alphabetic letters, or plural* litterae*, piece of writing) elements*" (p. 1). *That Dragon, Cancer* consists of fourteen scenes or chapters in which the player is allowed to follow Joel's and his parent's journey from, to paraphrase Susan Sontag's (1978:3) famous words, 'the kingdom of the well' to 'the kingdom of the sick'. The narrative and literary qualities of the game are emphasized by the use of a strong narrative voice belonging foremost to Ryan Green and are further emphasized by text being scribbled down at the same time as the player is confronted with the story of Joel's fate. In turn, the ludic dimension of the narrative consists both of the fact that the player must explore the setting where the narrative takes place, and of the small mini-games drawing from a wide range of traditional video and computer game genres, that one must play through to advance in the game. For example, these mini-games concern controlling balloons so that they do not crash into threatening cancer cells, or navigating a Mario Kart-like hospital trolley through the hospital's corridors to collect points in the form of various medications and treatments.

On a graphic and stylistic level, the game gives a rather abstract impression (cf. Schott, 2017:6), and from the beginning, it clearly is not striving for realism. For example, it is impossible to discern the facial features of the characters in the game or to identify the setting. Like the characters, the setting is stripped of any obvious identity markers connecting it to a reality outside the game. However, from the player's perspective, the effect of these aesthetic choices is to allow the players truly to immerse themselves in the gameplay. It could be said that the game's abstract nature, especially when it comes to the characters, allows the players to adopt the caregiver role, which, as pointed out, is the *raison d'être* of the game.

Also, when it comes to the actual game moments, it is often difficult to know what one is expected to do as a player. Rather than seeing this as a fault in the game, one can interpret it as another way to make the player experience the feeling of being in a situation like the one the Greens had to live through, in which one simply does not know how to act. The gameplay largely builds on the player's active exploration of the various and often difficult situations s/he is presented with. In this regard, *That Dragon, Cancer* could more generally be said to adhere to the popular video game genre of the adventure video game or explorative game. Specifically, when it comes to illness narratives it could be said to adhere to Frank's (1995) description of the 'quest narrative' in which Joel's cancer diagnosis, at least from the player's perspective, *"is the occasion of a journey that becomes a quest"* (p. 115).

The game's adventure- and quest-like character does not imply that it urges the player to move forward quickly, which is the case in most commercial adventure games. On the contrary, when it comes to speed, *That Dragon, Cancer* could be compared to what Ensslin (2014) calls a 'slow game', forcing its player *"to proceed at an extremely slow pace, thus evoking a meditative mood"* (p. 142). As Ensslin (2014) points out, this design feature will *"give players breathing space and further exploratory options, to make them reflect on their actions"* (p. 142). A fact that in *That Dragon, Cancer* goes hand in hand with the aim of giving the player knowledge of what it means to care for a deathly ill child.

The game opens on a paradisiacal scene of Joel sitting by a lake feeding birds, while the second scene shows Joel playing in the playground. Both these introductory scenes express harmony and joy which is emphasized by the musical score of calm classical music. At the same time the disease lingers in the background, as becomes evident through the sound recordings of Ryan and Amy's discussions and Amy's voicemails. After these introductory scenes, the player gradually faces different situations the Greens confronted during Joel's short life; from the time of his cancer diagnosis to medical treatment and finally his death. The setting changes from the beautiful and brightly lit landscape, to the dark rendering of the hospital.

The famous Youtuber PewDiePie's playthrough clearly attests to the extent to which the game emotionally activates the player. With tears in his eyes, he exclaimed *"I can't play this! It's too much"*, and after playing two-thirds of the game, he concluded: *"It was very, very heavy"* (PewDiePie, 2016). The enormous number of comments on the video (nearly 28,000) reporting the feelings of the viewers of PewDiePie playing the game underscores the emotional aspect of the game. The fact that, *That Dragon, Cancer* manages to arouse the player's feelings to such an extent makes it part of a trend of so-called serious video games (Breuer & Bente, 2010) or knowledge games (Schrier, 2016) which let players get emotionally involved in what it means to live with a disease or, as is the case of the Greens, to be affected by it in other ways. In this regard, one could mention the example of Zoe Quinn's *Depression Quest* (2013), which lets the player experience living with depression from the inside. In doing so, *Depression Quest*, as stated on the website devoted to the game,

> "*aims to show other sufferers of depression that they are not alone in their feelings, and to illustrate to people who may not understand the illness the depths of what it can do to people*" (Quinn, 2013).

While it could be argued, that *That Dragon, Cancer* on a general level is part of this broader video game trend it nevertheless stands out in comparison with other games taking cancer as their subject, such as *Remission 1* and *2*, created by Hopelab, "*a social innovation lab focused on designing science-based technologies to improve the health and well-being of teens and young adults*" (Wikipedia). In these games, which are specially intended for players with a cancer diagnosis, the player controls a nano-robot that fights cancer cells inside cancer patients' bodies. As in a first-person shooter game, the player tries to defeat cancer using various weapons such as chemotherapy, radiation, and antibiotics. The *Remission* series strongly adheres to a view of cancer as an enemy to be defeated and it reproduces the conceptual understanding of the cancer patient as involved in a war on cancer that Susan Sontag had already critiqued in the 1970s in her famous book *Illness as Metaphor* (1978).

In *That Dragon, Cancer*, this war is in a way lost beforehand. There is no victorious ending, no comic plot. From the beginning, not least from the paratextual elements (Genette, 1997) surrounding the game, the player is aware of its outcome: Joel's inevitable death. As hinted at above, and emphasized by Gareth Schott (2017), this knowledge removes the "*desire to advance as efficiently and quickly as possible*" (p. 7). Thus, this game works against the logics of most computer and video games, the goal of which is often to proceed as quickly as possible from one challenge to another. As a player of *That Dragon, Cancer*, one simply wants to postpone the inevitable and let Joel live a little bit longer.

Conclusion

Let us conclude by returning to Arthur Frank's (1995) statement: "*Illness calls for stories*" (p. 54). As this exploratory study of the use of digital media to narrate experiences of cancer shows, digital media have opened up for many ways to answer this call, from blogs to digital open-source projects and video games. And, as stated in the introduction, one could easily expand the palette of digital illness narratives by, for example, considering the sharing of illness narratives about cancer in social media, on Facebook, Twitter, and YouTube.

One thing that becomes especially evident in the analyzed material, is how doing illness in digital media concerns various relationships with an implied or real audience. The most striking aspect is how Gidlund, Iaconesi and the Greens, in different ways, work both with and against their digital medium, regarding the matter of interaction and participation. From the viewpoint of the audience, the blog, open-source project, and video game arguably constitute different participatory cultures. In this regard, *La Cura* stands out by fully embracing the interactive and participatory potential of digital media. In its entirety, it was dependent on the audience and its willingness to involve itself in co-creation. There was also from the beginning an explicit ambition from Iaconesi's side to make his personal experience of disease into a collective concern. One prerequisite for the project was, that after disclosing his personal narrative of illness on YouTube, he chose to abandon his authorial control over what the audience would do with it, assuming a curatorial role instead. *La Cura* in a fundamental way resembles the fan cultures investigated by Henry Jenkins (2006, 2008), in which the fans actively embrace and expand the stories they at the same time consume.

Also, in the video game *That Dragon, Cancer*, the player is invited to interact and participate in doing cancer but in a different way. Although the gameplay allows the player to assume the role of caregiver, the interactive and participatory dimension is limited by the game, which lets him or her move through a number of preplanned narrative steps. As a player, one cannot influence the narrative in any direct way. Yet, it is hard as a player not to engage emotionally, which is emphasized by the opportunities for the player to linger in various situations, caring for the deathly ill Joel.

Finally, in comparison with *La Cura* and *That Dragon, Cancer*, the blog *In My Body* distinguishes itself by the way Gidlund acknowledges but explicitly declines the interactive and participatory dimension often viewed as one of the most prominent medium-specific features of the blog format. Even though, it was initially intended for passive reading the blog soon created an engaged audience of commenters. Together, its readers opened up and transformed the blog into a platform for collectively sharing experiences of cancer. This illustrates that doing cancer in digital media is not only up to the blog author, video game maker, or curator, but is also up to the audience and its motivation to interact and participate.

References

Aaslestad, P. (2009). *The Patient as Text. The Role of the Narrator in Psychiatric Notes, 1890-1990.* (Erik Skuggevik & Deborah Dawkin, Trans.). Oxford & New York: Radcliffe Publishing.

Andersson, Y. (2017). Blogs and the Art of Dying. Blogging With, and About, Severe Cancer in Late Modern Swedish Society. *OMEGA - Journal of Death and Dying. Online First,* July 2017, 1-20. https://doi.org/10.1177/0030222817719806

Arduser, L. (2017). Remediating Diagnosis. A Familiar Narrative Form or Emerging Digital Genre. In Carolyn R. Miller & Ashley R. Kelly (Eds.), *Emerging Genres in New Media Environments* (pp. 63-78). Cham: Palgrave Macmillan. https://doi.org/10.1007/978-3-319-40295-6_3

Bolaki, S. (2016). *Illness as Many Narratives. Arts, Medicine and Culture*. Edinburgh: Edinburgh University Press. https://doi.org/10.3366/edinburgh/9781474402422.001.0001

Bolter, J. D. & Grusin, R. (1999). *Remediation. Understanding New Media*. Cambridge, Massachusetts: MIT Press.

Breuer, J. & Bente, G. (2010). Why So Serious? On the Relation of Serious Games and Learning. *Journal for Computer Game Culture*, 4(1), 7-24. http://www.eludamos.org/index.php/eludamos/article/view/vol4no1-2/150 (accessed 2.9.2018)

Brough, M. (2014). Participatory Culture. In Marie-Laure Ryan et al. (Eds.), *The Johns Hopkins Guide to Digital Media* (pp. 382-387). Baltimore: Johns Hopkins University Press.

Bruns, A. (2008). *Blogs, Wikipedia, Second Life, and Beyond. From Production to Produsage*. New York: Peter Lang.

Bury, M. (1982). Chronic Illness as Biographical Disruption. *Sociology of Health & Illness,* 4(2), 167-182. https://doi.org/10.1111/1467-9566.ep11339939

Conway, K. (2007). *Beyond Words. Illness and the Limits of Expression*. Albuquerque: New Mexico Press.

Couser, G. T. (1997). *Recovering Bodies. Illness, Disability, and Life Writing*. Madison, Wisconsin: The University of Wisconsin Press.

Couser, G. T. (2009). *Signifying Bodies. Disability in Contemporary Life Writing.* Ann Arbor: University of Michigan Press. https://doi.org/10.3998/mpub.915367

Couser, G. T. (2017). *The Future of Life Writing: Body Stories*. a/b Auto/Biographical Studies, 32(4), 379-381. https://doi.org/10.1080/08989575.2017.1289016

Delfanti, A. & Iaconesi, S. (2016). Open Source Cancer: Brain Scans and the Rituality of Biodigital Data Sharing. In Darin Barney, et al. (Eds.), *The Participatory Condition in the Digital Age* (pp. 123-143). Minneapolis: University of Minnesota Press.

Diedrich, L. (2007). *Treatments. Language, Politics and the Culture of Illness*. Minneapolis: University of Minnesota Press.

Ensslin, A. (2014). *Literary Gaming*. Cambridge. The MIT Press. https://doi.org/10.7551/mitpress/9450.001.0001

Frank, A. (1995). *The Wounded Storyteller. Body, Illness, and Ethics*. Chicago: University of Chicago Press. https://doi.org/10.7208/chicago/9780226260037.001.0001

Garde-Hansen, J. & Gorton, K. (2013). *Emotion Online. Theorizing Affect on the Internet*. Basingstoke, Hampshire: Palgrave Macmillan. https://doi.org/10.1057/9781137312877

Genette, G. (1997). *Paratexts. Thresholds of Interpretation*. Cambridge: Cambridge University Press.

Gidlund, K. (2011). *Det finns något som jag måste berätta. I kroppen min*. https://ikroppenmin.blogspot.com/2011/03/det-finns-nagot-som-jag-maste-beratta.html (accessed 21.8.2018)

Gidlund, K. (2013a). *Gam. I kroppen min*. http://ikroppenmin.blogspot.com/2013/04/gam.html (accessed 21.8.2018)

Gidlund, K. (2013b). *I kroppen min. Resan mot livets slut och alltings början*. Stockholm: Forum.

Gidlund, K. (2013c). *I kroppen min. Vägsjäl*. Stockholm: Forum.

Gubar, S. (2016). *Reading & Writing Cancer. How Words Heal*. New York: W. W. Norton & Company.

Hale, B. J., Gonzales, A. L. & Richardson, M. (2018). Vlogging Cancer. Predictors of Social Support in YouTube Cancer Vlogs. *Cyberpsychology, Behavior, and Social Networking*, 21(9), 575-581. https://doi.org/10.1089/cyber.2018.0176

Hawkins, A. H. (1999). *Reconstructing Illness. Studies in Pathography*, 2. ed. West Lafayette, Indiana: Purdue University Press.

Iaconesi, S. (2012a). *La Cura - The Cure*. https://web.archive.org/web/20130719054951/http://opensourcecureforcancer.com:80/ (accessed 27.3.2019)

Iaconesi, S. (2012b). *My Open Source Cure*. YouTube 10.9.2012. https://youtu.be/5ESWiBYdiN0 (accessed 3.9.2018)

Jenkins, H. (2006). *Fans, Bloggers, and Gamers. Exploring Participatory Culture*. New York: New York University Press.

Jenkins, H. (2008). *Convergence Culture. Where Old and New Media Collide*. New York: New York University Press.

Jurecic, A. (2012). *Illness as Narrative*. Pittsburgh: University of Pittsburgh Press. https://doi.org/10.2307/j.ctt5hjr8p

Kennedy, J. (2016). In the Blood. Mapping Narrative Circulation in Online Leukemia Networks. In Helen Thomas (Ed.), *Malady and Mortality. Illness, Disease and Death in Literary and Visual Culture* (pp. 59-72). Newcastle upon Tyne, UK: Cambridge Scholars Publishing.

Lichty, P. (2012). *La Cura: An Open Source Cure. An Interview with Salvatore Iaconesi. Furtherfield*. https://www.furtherfield.org/la-cura-an-open-source-cure-an-interview-with-salvatore-iaconesi/ (accessed 21.8.2018)

Lind, R. A. (Ed.) (2012). *Produsing Theory in a Digital World. The Intersection of Audiences and Production in Contemporary Theory*. New York: Peter Lang.

Lind, R. A. (Ed.) (2015). *Produsing Theory in a Digital World 2.0. The Intersection of Audiences and Production in Contemporary Theory*. New York: Peter Lang. https://doi.org/10.3726/978-1-4539-1629-2

Lindroth, M. (2013). *Klarsynt gåva från dödens väntrum*. Göteborgs-Posten 10.5.2013.

McNeill, L. (2003). Teaching An Old Genre New Tricks. The Diary on the Internet. *Biography*, 26(1), 24¬-47. https://doi.org/10.1353/bio.2003.0028

Nesby, L. & Salomonsen, A. (2016). Youth Blogging and Serious Illness. *Medical Humanities*, 42(1), 46-51. https://doi.org/10.1136/medhum-2015-010723

Osit, D. & Zouhali-Worrall, M. (2015). *Thank You for Playing*. http://www.thankyouforplayingfilm.com (accessed 11.3.2019)

Page, R. E. (2012). *Stories and Social Media. Identities and Interaction*. London: Routledge https://doi.org/10.4324/9780203148617

PewDiePie. (2016). *This Game Will Make You Weep (That Dragon, Cancer)*. YouTube 29.3.2016. https://www.youtube.com/watch?v=xBQYLXX2Mk0 (accessed 11.3.2019)

Quinn, Z. (2013). *Depression Quest*. http://www.depressionquest.com/#info-section (accessed 1.9.2018)

Rettberg, J. W. (2014). *Blogging*. Cambridge: Cambridge University Press.

Schmidt, W. (2013). Implied reader. In Peter Hühn et al. (Eds.), *The Living Handbook of Narratology*. Hamburg: Hamburg University Press. hup.sub.uni-hamburg.de/lhn/index.php?title=Implied Reader&oldid=2015 [accessed 1.3.2019]

Schrier, K. (2016). *Knowledge Games. How Playing Games Can Solve Problems, Create Insight, and Make Change*. Baltimore: John Hopkins University Press.

Schott, G. (2017). That Dragon, Cancer. Contemplating Life and Death in a Medium that has Frequently Trivialized Both. DiGRA *'17. Proceedings of the 2017 DiGRA International Conference*, 14, 1-10. http://www.digra.org/digital-library/publications/that-dragon-cancer-contemplating-life-and-death-in-a-medium-that-has-frequently-trivialized-both/ (accessed 21.8.2018)

Sontag, S. (1978). *Illness as Metaphor*. New York: Farrar, Straus & Giroux, cop.

Sorapure, M. (2003). Screening Moments, Scrolling Lives. *Biography* 26(1), 1-23. https://doi.org/10.1353/bio.2003.0034

Stage, C. (2017). *Networked Cancer. Affect, Narrative and Measurement*. Cham: Palgrave Macmillan. https://doi.org/10.1007/978-3-319-51418-5

Tembeck, T. (2017). Autopathographies in New Media Environments at the Turn of the 21st Century. In Carolyn R. Miller & Ashley R. Kelly (Eds.), *Emerging Genres in New Media Environments* (pp. 207-223). Cham: Palgrave Macmillan. https://doi.org/10.1007/978-3-319-40295-6_11

That Dragon, Cancer. (2016). *Numinous Games*. http://www.thatdragoncancer.com/#home (accessed 11.3.2019)

Williams, S. (2000). Chronic Illness as Biographical Disruption or Biographical Disruption as Chronic Illness? Reflections on a Core Concept. *Sociology of Health & Illness*, 22(1), 40-67. https://doi.org/10.1111/1467-9566.00191

Wikipedia. *HopeLab*. https://en.wikipedia.org/wiki/HopeLab (accessed 3.9.2018)

Originalartikel

Cancer Narratives on Social Media as ‘Small Stories’

An investigation of positioning, supportive (dis)alignment and tellability crises in cancer storytelling on Instagram

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Cancer narratives shared on social media platforms have received increased academic interest over the last decade but often without sufficiently acknowledging the media specific narrative affordances of these platforms. The article will address this problem, by first presenting a ‘small stories’ approach to studying illness narrative on social media and then putting the approach to work in a case study of a Danish cancer patient’s Instagram profile (@jannelivsnyder66). The paper argues, that the storytelling practices on the profile can be analytically approached by focusing on the interplay between three co-constitutive levels of interaction: 1) a level of the desired illness narrative and position that the narrator, influenced by available cultural discourses and interaction with followers, hopes to be able to tell; 2) a level of sharing everyday posts, which can either support or disturb the desired narrative; 3) a level of follower responses, where relations between the desired narrative and singular posts are monitored through processes of liking and commenting. Followers *of social media cancer narratives should in light of this not be understood as an audience witnessing an individual telling his/her "own" story, but rather as crucial contributors to the social interaction and co-creation of desired narratives, subject positions, narrative progress and tellability. In conclusion, the article thus stresses that cancer storytelling on social media, despite the strong biological connection of the disease to an individual body, emerges through inherently social processes of reading, liking, commenting, monitoring and co-deciding narrative practices.*

Introduction

Social media is a new important platform for (semi)public narrations of illness, and cancer narratives shared on social media platforms; such as blogs, Facebook, Instagram and YouTube (Kaplan & Haenlein: 2010; Klastrup, 2016) have in particular received increased academic interest over the last decade (Andersson: 2017; Coll-Planas & Visa: 2016; Heilferty: 2018; Nesby & Salamonsen: 2016; Orgad: 2005; Pitts: 2004). However, I would like to argue that analytical approaches to this type of narrative material are still largely modelled on typologies and definitions developed in literary studies aimed at understanding book-based illness narratives (Frank: 1995; Hawkins: 1999; Jurecic: 2012). With a few exceptions (McCosker: 2013; Page: 2012; Stage: 2017), social media cancer narratives are treated as though they were books, that is, as fossilized textual entities characterized by a particular narrative structuration of past events and with a single dominant narrator communicating his or her individual story to a passive audience of receivers. This implies, that the dynamic 'living' (Ochs & Capps: 2002) and interactional aspects of narrating cancer on social media are repeatedly downplayed – or at least not sufficiently integrated into the methodologies developed to approach this type of storytelling activity.

The aim of this article, is to present a 'small stories' approach (Bamberg & Georgakopoulou: 2008) to studying illness narrative, in order to better acknowledge social media as a dynamic and interactional storytelling platform. The small stories tradition has thus far not played a prominent role in studying illness narratives but I argue that it is becoming increasingly relevant as more and more illness experiences are shared and developed on social media. This approach is not solely relevant for understanding cancer storytelling on social media but can be used in any exploration of illness experiences narrated through the temporal and interactional affordances of social media. For that reason, this article primarily contributes to research interested in the media-specific characteristics of social media illness narratives and secondarily to the specific strand of narrative research dealing with cancer experiences.

In the article, I will apply the 'small stories' theoretical approach to the communication taking place on a female cancer patient's Instagram profile: *@jannelivsnyder66* made by Janne Hinrichsens (born 1966) (2880 followers, 2216 following). My empirical material will comprise the 403 posts shared between November 2015 (when the profile was established) and June 2018 (when the empirical material was collected). I selected this case study because Janne highlights and directly addresses some of the often more hidden interactional logics that characterize social media cancer narratives. This specific case is clearly too empirically limited to offer generalizations to understand a wider population of cancer patients, but it will hopefully provide preliminary theses about the narrative and interactional dynamics of sharing cancer experiences on social media and thus will hopefully contribute new knowledge to the budding field of social media illness narratives.

When analyzing and coding the posts on *@jannelivsnyder66*, I was particularly interested in important differences in how Janne positions herself over time and how Janne interacts with followers. To establish an overview of types of communicative content and sharing practices, and changes during the lifespan of the profile, I began coding the material through an explorative process of categorizing the 403 posts in relation to types of content, modes of sharing, use of selfie types, and the number of comments/likes. I also took notes on the overall commenting practices of the profile. Not all the coding results are directly relevant to this article, but they all helped to reveal the narrative and interactional dynamics I address here.

In terms of ethics, the collection of empirical material is based on Janne's informed consent, all the users who commented on the Instagram profile have been anonymized, and Janne was offered the chance to read and comment on the article before it was published (Ess & AoIR ethics working committee: 2002, 4; Markham & Buchanan : 2012, 4).

Illness narratives on social media as an interactional practice

When investigating 403 posts about a person's illness, it is tempting to somehow 'stabilize' the material as an enclosed set of posts characterized by inherent textual and narrative traits instead of understanding it as having taken part in dynamic processes of interaction between interlocutors, in which, the articulation of illness can change over time and be influenced by the communicative situation. The 'small stories' approach is precisely an attempt to avoid this temptation and to, instead, treat social media narratives as an *evolving practice* that is constantly shaped and reshaped in continuous interaction about the 'here and now' of illness (what has happened since the last post?) and not as a *coherent textual construction organizing past events*.

The 'small stories' approach to narrative studies revises a more traditional understanding of narrative as described by Labov and Waletsky (among others). In 1967, Labov and Waletsky formulated a *formal* and *functional* definition of narrative in oral interaction, which understands narrative as linked to the articulation of non-shared personal experiences of sequential events taking place in the past (Labov & Waletsky : 1967). According to Michael Bamberg, this formalist line of thinking is contrasted by an approach in which narrative is instead understood as part of "human interactive practices" played out between interlocutors (Bamberg, 2016: 1288). The 'small stories' line of thinking entails also that narratives are understood as crucial for the negotiation of social positions and identities. Such a line of thinking stresses that we use narratives to 'position' ourselves in relation to others and in various forms of communities and thus to make "sense of who we are" (Bamberg, 2016: 1294). Through this analytical focus, 'small stories' are treated *"as a window into the micro-genetic processes of identities as 'in-the-making' or 'coming-into-being'"* (Bamberg & Georgakopoulou: 2008, 379).

Practice, the self and interaction are in other words at the core of a small stories approach to narratives. According to Bamberg, such an approach must begin with the assumptions that 1) *"narrative activities are embedded in previous and subsequent turns, that is,* interactive before and after" (Bamberg: 2016, 1292), which invites us to focus on the role of narrative elements in the ongoing flow of interaction, and 2) *"narrating activities require a great deal of interactive negotiation"* (Bamberg: 2016, 1292), which implies, that we must focus on how interlocutors collaborate on creating narrative elements, in particular, communicative situations.

Other important differences between the formalist 'narrative-as-text' traditions and the 'small stories' approach are: 1) *Temporal orientation*: narrative-as-text traditions prioritize past events, while the 'small stories' approach directs us towards the sharing of *"breaking news"* (Georgakopoulou: 2006, 126), the "*moment*" or "*recent* ('this morning', 'last night') or still-unfolding events" (Bamberg and Georgakopoulou: 2008, 381). 2) *Tellership*: narrative-as-text traditions often focus on one teller, while ‘small stories’ are understood as co-constructed by interlocutors in everyday settings (e.g. on social media). 3) *Tellability*: narrative-as-text traditions prioritize the representation of extraordinary experiences, while the ‘small stories’ approach is equally interested in *“seemingly uninteresting tidbits”* (Bamberg and Georgakopoulou: 2008, 381), everyday occurrences, *“shared (known) events, but also allusions to tellings, deferrals of tellings, and refusals to tell”* (Georgakopoulou: 2006, 123). This implies that ‘tellability’, evaluating when a particular occurrence is worth telling, is not only a quality that a certain event/story *has* but is also a quality negotiated *collectively* in the interactive situation.

Illness, social media and small stories

A large amount of valuable research has been conducted on personal illness narratives in the narrative-as-text tradition, which has, among other things, focused on different genres of illness narratives in books (Charon: 2006; Couser: 2016; Frank: 1995; Hawkins: 1999) and the role of various types of metaphors within these narratives (Hawkins: 1999; Sontag: 1991). Research on illness narratives on social media that explicitly transgress the formalist or textualist model is rare. Exceptions are Shani Orgad’s investigation of cancer storytelling online (Orgad: 2005, 39) or the work of Ruth Page, who, with respect to her analysis of illness blogs, elaborates on some of the characteristics of social media illness narratives:

> *“(…) the stories that narrators tell about their experiences of illness are not told retrospectively from the point of recovery, but as updates that appear discontinuously as the narrator documents their experiences while diagnosis and treatment unfold. Sometimes the sequence of blog posts stops altogether without warning, perhaps for the distressing reason that the narrator is too ill to continue to write, or has even died. Within the episodic archives or social media posts, there may be little causal connection between one entry and the next”* (Page: 2012, 10).

Although, this kind of academic interest in the dynamism of illness narratives on social media is uncommon it is still possible to find useful research on the more general characteristics of social media storytelling as small stories, which can also be used to analyze accounts of illness. Most significantly, Alexandra Georgakopoulou has shown how social media sites are prominent cultural sites for small storytelling (Georgakopoulou: 2016c, 268). Stories shared on social media are thus often characterized by multiple authorship, open-endedness, and a desire to capture the moment through narrative fragments. These small stories characteristics are supported by the affordances of many social media platforms that encourage the small-scale sharing of current experiences, moments, emotions, opinions and geographical embeddedness.

Switching from small story posting to small story response, Georgakopoulou has identified two different modes of *positive story recipiency* (Georgakopoulou, 2016b: 308) through followers commenting on the post. The first is 'ritual appreciation', which is a short recognition often used in relation to selfies (Georgakopoulou: 2016b), that "*involves positive assessments of the post and/or poster*" (Georgakopoulou: 2016b, 301). Ritual appreciation thus "*serves as the visual counterpart of lots of people clapping and cheering at the same time*" (Georgakopoulou: 2016b, 310). The second is 'knowing participation', which involves commenters adding knowledge about the post's backstory (Georgakopoulou: 2016a, 197) or hinting at offline relationships. These responses can be seen as different types of 'alignment' through which "*speakers signal, linguistically, paralinguistically and in embodied ways, their understanding of their interlocutors' positions*" (Georgakopoulou: 2016a, 179). Followers can of course also choose to disalign from the post by opposing it in various degrees with their comment, most notably through antagonistic strategies of trolling (Phillips: 2011), but also through processes of debating, contesting or dissenting (Knudsen & Stage: 2012).

A potential objection to using the 'small stories' approach is that it fails to address how larger storylines are also expected and produced on social media and how illness narratives, for example, often reintroduce a seemingly more centralized narrator (the patient) and dramatic occurrences (receiving treatment to survive) as material for storytelling. In this way, cancer narratives on social media sometimes seem too big and existential to be called small. This idea resonates with Mark Freeman's defense of 'big stories', which maintains that we still require concepts to describe narratives that reflect on (and often look back on) larger periods of life and existence:

> "*Big stories are those narratives, often derived from interviews, clinical encounters, and other such interrogative venues, that entail a significant measure of reflection on either an event or experience, a significant portion of a life, or the whole of it*" (Freeman: 2006, 2).

However, I would argue, that this point in some sense misses the practice orientation of the 'small stories' framework. Even telling 'big stories' about life or existence is always a highly contextual and situated activity. 'Big stories' are always told *by* someone and *to* someone for *some* reason and they depend on interaction and feedback for their continuation, development and social effects (Bamberg: 2006). For this reason, it might be more worthwhile to ask *how* larger storylines about (the self during) illness are constructed and developed over time through interaction between patients and receivers. And why some cancer experiences do not develop into larger storylines as they are not responded to or interacted with by an engaged audience online? In other words, serious illness does not in itself produce a change of storytelling premises that prompts the patient to withdraw from social interaction in order to independently reflect on and articulate his or her 'big' illness story. Serious illness as a 'biographical disruption' (Bury: 1982) does not isolate the patient in terms of managing and telling illness stories. On the contrary, patients' narratives about themselves are constantly influenced by, and curated to fit into, social interactions with relatives, friends, co-patients, medical authorities, or cancer bloggers while also taking up or renegotiating cultural discourses of illness not produced by the patient.

Furthermore, platform logics and affordances need to be considered when studying social media cancer narratives and interaction. Social media are not innocent channels where patients simply articulate their experiences. They are rather platforms with affordances that condition, prioritize and disseminate particular forms of storytelling, and there are important narrative and interactional differences between specific platforms. Instagram, the core provider of material for this article's analysis, was launched in 2010 and bought by Facebook in 2012. Instagram is a 'social networking site' (SNS), just like e.g. Twitter and Facebook (boyd: 2011; Kaplan & Haenlein: 2010), and has its own characteristics and constraints. Firstly, Instagram (in contrast to e.g. Facebook and Twitter) gives prominence to visual communication (Ibrahim: 2015). The name Instagram fuses 'instant (camera)' and 'telegram' and thereby underlines the immediate production and transmission of a combination of something visual with something written (and short) as its core form of communication. The relative briefness of the narrative input is supported by the fact that the maximum length of text allowed in a post is 2.200 characters. Secondly, Instagram pushes users towards using mobile technologies, like smartphones, by making it difficult to upload pictures onto Instagram from the website, and thus from laptops. This constraint prioritizes on the move sharing of photos from mobile devices as the desired mode of communication (Marwick: 2015). The platform thus affords 'networked photography', which refers to *"the practice of sharing photographs immediately after capture in real-*

time, mobile visual communication, using, for example, instant messaging (IM) tools or social media applications" (Lobinger: 2016, 475). Thirdly, Instagram, besides linking people with established strong ties (like Facebook), prioritizes a more hierarchical fan-like relation between 'the followed', who produces visual input, and 'the followers', who takes on the role of responding to visuality through the heart/like button or comments.

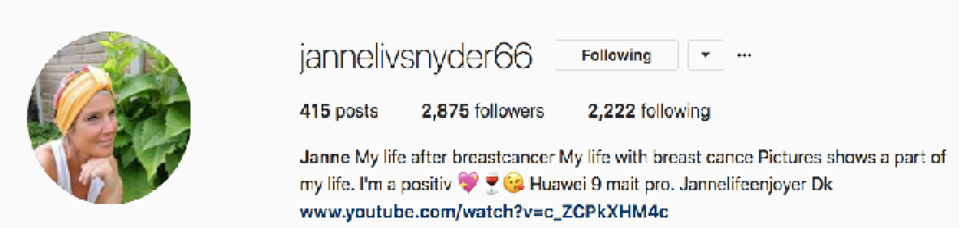
Focusing on the cultural implications of using the platform of Instagram, scholars have argued that it contributes to an 'aestheticization' of the mundane through 'banal imaging' (Ibrahim: 2015). This fusion of aesthetics and everyday life, has supported the rise of a new segment of talented entrepreneurial influencers on Instagram with well-developed skills and competencies in terms of visual presentation, and productions of selfies (Abidin: 2016) – which are crucial for gaining popularity, or 'instafame' (Marwick: 2015), on the platform. This point stresses, that Instagram not only prioritizes a particular type of storytelling, based on visual, short and continuous narrative contributions, but also, that it is easier to navigate successfully for individuals with particular communicative and technological competences. This indirectly implies that specific patient groups (e.g. well-educated patients), illnesses (e.g. well-known and aesthetically unobtrusive ones) and illness experiences (e.g. those able to transform into appealing or spectacular selfies) are often more likely to be gain attention and traction on Instagram.

Narrative and interactional practices on @ *jannelivsnyder66*

Janne Hinrichsen (born 1966) made her first post on the profile *jannelivsnyder66* in November 2015. In June 2018, when the empirical material was sampled for analysis, the profile consisted of 403 posts. *Jannelivsnyder66*, which can be translated into English as *Janneenjoyeroflife66*, describes Janne's everyday life but also the diagnosis and treatment of her second breast cancer experience and mastectomy. At the time of writing, Janne is in remission from cancer. In the following analysis I will argue, that the photo-text-sharing practices on the profile can be analytically approached by focusing on the interplay between three co-constitutive levels of interaction: 1) the level of *the desired illness narrative and position* that the narrator, influenced by available cultural discourses and interaction with followers ,wants to tell (a narrative often focused on progressing towards a cure and expressed in bios or individual, more programmatic posts); 2) the level of *everyday posts that share moments* more or less directly related to illness experiences, which can either support or disturb the desired narrative; 3) the level of *follower responses (through hearts/likes and comments)*, where the alignment of the desired narrative and the individual posts are monitored through processes of liking and commenting. It is important to note that none of the three levels is stable or created outside social interaction. As such, the desired narrative does not simply express the inner thoughts of the ill person but is also co-constructed and renegotiated through day-to-day communication with interlocutors.

Positioning and desired narrative

Janne very explicitly describes the desired or intended narrative she wishes to convey about her illness, but she also describes the type of subject position with which she aligns herself. Her ideal narrative is clearly what Arthur Franks has described as the ‘restitution narrative’ (Frank: 1995), a narrative that moves from diagnosis to treatment to cure. but, more importantly, Janne wishes to tell the story of how this process of treatment and struggle can also be filled with joy and happiness. And her followers constantly validate that she is an extraordinarily positive, happy and funny person in their comments through ritual appreciation. In the profile bio, Janne positions herself as a positive and somewhat hedonistic person (cf. the name of the profile and the wine emoji) and, perhaps less consciously, as not overtly focused on perfection (cf. the lack of focus on typos):



415 posts 2,875 followers 2,222 following

Janne My life after breastcancer My life with breast cance Pictures shows a part of my life. I'm a positiv 💖🍷😘 Huawei 9 mait pro. Jannelifeenjoyer Dk
www.youtube.com/watch?v=c_ZCPkXHM4c

Ill. 1. Janne’s Instagram bio in June 2018

This self-positioning is also expressed in individual posts where her overall existential approach to life becomes an explicit theme:

> *“Just took a 7.4 km chemo-walk. No pain. Head is tired, but not the body. Spirit is high. The sun is shining. Life is great. And thank you so much to all of you following me. It is just as much you who makes me wanna share something on*

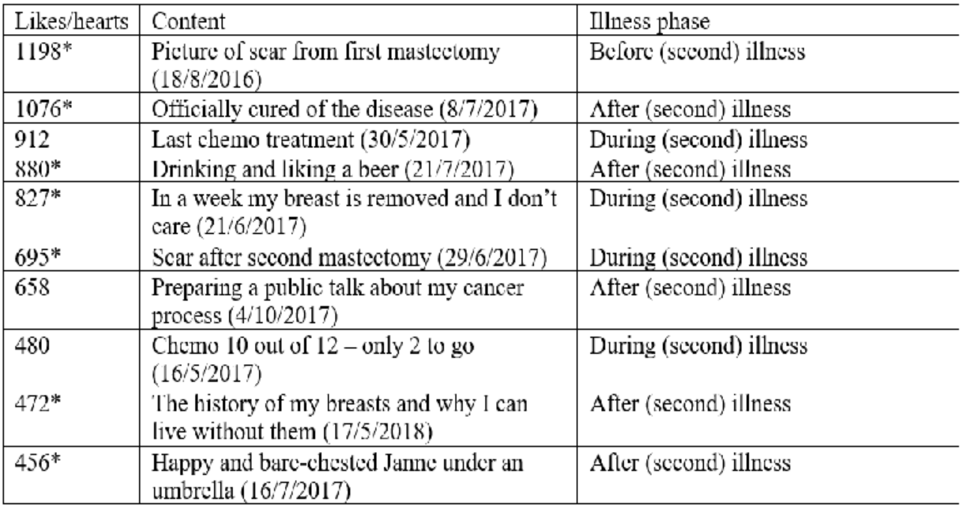
> *Instagram. I want to show how important it is to stay happy and keep believing in life. Lots of fighting spirit. Humour, happiness, a positive mind, exercise, support from family and friends are invaluable things. And once in a while, you should be allowed to be a little crazy and childish although you are 50 years old"* (28/3/2017).

An important part of her self-positioning is also expressed through optimistic pictures and selfies of her bare-chested or scared body. These pictures also underline Janne's happiness and pragmatic vitality; for example, the picture below (from 17/5/2018) is accompanied by a text that describes all the breast-related health problems that Janne has endured over the years and, therefore, how happy she is to have had a double mastectomy.

jannelivsnyder66 Det gode ved, ikke at have bryster er, at jeg får ikke patsved, når jeg tager solbad. 😀
Til dagligt går jeg sådanne her rundt. Jeg har jo ikke noget at skjule. Det er faktisk kun på arbejde, at jeg bruger mine proteser. Jeg er mig, som jeg ser ud nu. Jeg har ikke gode erfaringer med bryster. Da jeg begyndte, at få bryster, blev jeg drillet, fordi de så mærkelige ud. Som 19 årige tog jeg så til læge, og det viste sig, at jeg havde brok i brysterne. Jeg blev opereret af en kirurg i Odense. Han skar bryst vorterne af, og syede bryst vorterne på igen, men i mindre format. Det skulle gøres i to omgange, med et års mellemrum. Det gjorde desværre også, at jeg ikke kunne amme mine børn ordentligt. Så nej, jeg har kun haft bøvl med de bryster, og jeg er fuldstændig tilfreds med min krop uden. Jeg er jo stadigvæk

Ill. 2. "The good thing about not having breast is…"

This visual focus on scar images and selfies, and the female body living happily without breasts, gives the profile an almost activist touch. It incarnates the ideal of Audre Lorde's classic *The Cancer Journals* (1980), in which Lorde argued in favour of women with cancer renouncing their prostheses and taking the scared, bald, asymmetrically curved or flat body into the public sphere. This line of everyday body activism is clearly supported by Janne's followers. If we examine the 10 most-liked posts, 7 of them (marked with *) are images showing Janne as bare-chested, with one or two breasts removed, while smiling.



Likes/hearts	Content	Illness phase
1198*	Picture of scar from first mastectomy (18/8/2016)	Before (second) illness
1076*	Officially cured of the disease (8/7/2017)	After (second) illness
912	Last chemo treatment (30/5/2017)	During (second) illness
880*	Drinking and liking a beer (21/7/2017)	After (second) illness
827*	In a week my breast is removed and I don't care (21/6/2017)	During (second) illness
695*	Scar after second mastectomy (29/6/2017)	During (second) illness
658	Preparing a public talk about my cancer process (4/10/2017)	After (second) illness
480	Chemo 10 out of 12 – only 2 to go (16/5/2017)	During (second) illness
472*	The history of my breasts and why I can live without them (17/5/2018)	After (second) illness
456*	Happy and bare-chested Janne under an umbrella (16/7/2017)	After (second) illness

Ill. 3. The 10 most-liked posts on @jannelivsnyder66

In this way, liking seems to be particularly intense on the profile when posts express an image of the embodied self and an approach to serious illness that is aligned with the desired narrative of positivity. Through these peaks of liking, followers thus support the continuous micro-genetic co-production of Janne's identity as happy and optimistic, even during the hardships of cancer.

The intense response to these scar images is also culturally conditioned: On the one hand, the images are visually provoking as they show the flat and bare-chested female body which is still a rare image in today's society, but on the other hand, they resonate with a cultural reverence for cancer patients who are able to affectively transgress their illness, stay happy or perform vital actions of survival and struggle (Ahmed: 2010; Rose: 2006; Seale: 2002; Stacey: 1997). In this way, Janne's most-liked selfies are simultaneously culturally provoking and culturally desired: They allow women to embrace the scared and non-prosthetic body, but the intensified liking also seems to support the notion that happy cancer patients should be praised and acknowledged. Furthermore, Janne's scar selfies represent a certain 'aestheticization' of existential crisis that resonates with the desire for something visually spectacular, afforded by the platform logics of Instagram.

Supportive disalignment

On occasion, the smooth alignment of 1) the desired narrative and subject position, 2) the content of the shared post, and 3) follower responses through liking is disturbed. This occurs, when the shared moment in the post fails to correspond with the desired narrative of restitution and happiness. An example of this took place on May 29, 2017, which was the day before Janne's last chemotherapy treatment. Here, the post does not focus on progress towards a cure and happiness but rather shares a sense of sadness and insecurity:

> *"Off day, right from the very beginning. Couldn't wake up when I left my bed. Started freezing, madly, after breakfast as a sign of fever. I quickly took some painkillers, and the fever dropped. Just thought that it was really irritating as I was laying there feeling sorry for myself. I was supposed to be attending a Lady Walk together with my lovely friends, but regrettably, I can't. I have slept a little, and feel a little better, but I prefer to stay in bed for the rest of the day. Hopefully, I will be ready for the last chemo, tomorrow"* (29/5/2017)

This kind of post, which disturbs and, in some sense, threatens the narrative and affective self-understanding constructed previously through interaction on the profile cannot simply be liked (or given a heart) but calls for a comment. Comparing the ten posts that received the most likes and the ten posts that received the most comments, there are overlaps (4 posts). While the 'most liked' list primarily consists of posts that present news of progression that can be supported, the 'most commented' list also consists of posts that present news of progress being threatened or stalled. Below is a list of some of the comments on the post quoted above

- *I hope you get better soon. Don't be afraid. Everything is going to be all right. God bless you. Kiss🐦🐦🐦🐦*
- *Øv øv Janne 🐦tænker på dig og er sikker på du bliver helt klar til imorgen🐦🐦 (trans. "So sorry Janne. Thinking of you and I am sure that you will be completely ready for tomorrow")*
- *Nuuurhg sødeste pige da🐦.... godt at de fleste dage er gode ved dig - og i morgen er det sikkert væk - så hold ud🐦 (trans. "Sweetest girl! Luckily most days treat you well – and tomorrow it will be gone – so stay strong")*
- *Årh, kram til dig 🐦i dag er der brug for en sengedag. I morgen en ny dag 🐦🐦🐦 (trans. "Hugs for you. Today you need to stay in bed. Tomorrow is another day")*:

These comments are characterized by what I call 'supportive disalignment' where commenters do not align themselves with the shared negativity of post but instead try to transform the affective and narrative quality of the post by focusing on negativity as momentary – as a small bump in the road leading to a happy ending. The commenters thus insist that the post should be interpreted within a larger narrative framework of restitution and approached as a temporary digression. *"Remember the story that you want to tell; stay happy and on track"*, seems to be the point expressed through the comments. In this way, through supportive disalignment, commenters try to reconnect or realign Janne with the previously constructed subject position focused on progression and happiness. This underlines the idea that Janne is not simply telling her 'own' story but is telling a story together with her followers. And sometimes these followers actually take the lead by telling the story about Janne, as a happy and optimistic patient, to Janne if she forgets or begins to doubt it.

If posts divert from the desired narrative over a period of time, it can be argued that the poster is forced to engage in acts that reposition the overall story he or she hopes to tell in the future. This actually occurs after Janne is officially cured but realises that her 'post-illness' self will never be the same as her 'pre-illness' self. She increasingly acknowledges that her post-illness self is cognitively challenged, increasingly tired and incapable of doing the same things as before the second diagnosis. She slowly accepts that she will have to do less, and this new desired narrative gradually seeps into her posts – often through descriptions of her long-lasting 'kemohjerne' (trans. 'chemo brain'). This change in the narrative also underlines how her profile is a platform for micro-genetic negotiations of constancy and change in relation to (the capacities of) the self.

Tellability crisis

Janne's profile shows how describing a serious illness increases a story's tellability in relation to a particular audience of other patients or followers interested in the disease. As such, once Janne is cured of cancer, a rather peculiar narrative situation is created. I refer to this situation as a 'tellability crisis', and it describes the moment when the drama of fighting death is replaced with descriptions of more mundane occurrences of living a normal life. Janne addresses this quite explicitly in a post:

> *"This morning I ran 3.7 km. Really nice. I hope that you want to help me a little bit. I am not so enthusiastic about Instagram at the moment. I can't figure out if I should share something like a normal cured person or if I should continue with something related to breast cancer and the life I am now leading as a former breast cancer patient. What do you think?"* (28/4/2018).

In the 34 comments on the post, Janne's followers overwhelmingly encourage her to 'be herself' and share whatever she feels like. This post is interesting, because it indirectly acknowledges that many people only followed Janne's profile because she was fighting a serious illness, and, now that she is cured, a fundamental relational problem arises. Her followers may ask: If we began following, you because you were fighting cancer and now you no longer have cancer, why should we still follow you?

Janne addresses this crisis of tellability by inviting her followers to co-create what should now be the logic of affective and narrative exchange on the profile. The previous collective contract, that fighting cancer is a highly tellable subject in relation to her followers, no longer seems to hold, and Janne thus engages her readers in redefining what about her life is now tellable. This example illustrates, that sharing stories of illness on social media is played out in a media space, where identity, relations and tellability are constantly redefined and negotiated through interaction, but it also shows that social media cancer profiles are often characterized by shifting 'curves of tellability' in relation to particular groups of audiences.

Conclusions

In this article, I have shown that Janne's social media cancer experiences are constantly narrated in a tension between 1) a desired narrative positioning of Janne and her illness process, 2) individual posts that can either support or disturb the desired positioning and 3) comments that to a large extent can be understood as narratively and affectively monitoring the relationship between the desired narrative and the singular posts. The primary interactional role of the comments thus seems to be to encourage Janne to align each individual post with the desired narrative and to guide the posts back on track when necessary. Posts that are "on track" mostly attract ritual appreciation and likes, while disturbing posts of worsening conditions or crises attract comments that supportively disalign with the disturbance of the post in order to move the story back on track. If the desired narrative faces continuous disruptive posts, it may have to be redefined, along with the subject position offered by the narrative (for example, Janne that has to acknowledge that she is cognitively challenged after the cancer treatment). In this way, comment responses seem to align with the post during positive times and supportively disalign with the post during crises.

Sharing the moment through social circulation, in other words, in light of past events and unknown future events (and narratives), provides the basic storytelling logic of Janne's Instagram-profile, but serious illness and treatment related to cancer also seem to 'traditionalize' the profile by creating a more clearly demarcated main theme (cancer) and an expectation that the narrative will hopefully progress through linear phases that move towards restitution. This support findings from other work on existential uses of social media, such as Korina Giaxoglou's work on mourning practices on Facebook:

> *"In terms of narrative form, they seemingly resemble the Facebook status updates studied by Page (2012) in their smallness and story-like fragmentary shape; and yet they are also seen to differ markedly from Facebook status updates in the clustering of their narrative dimensions towards the polished end of the narrativity continuum (Ochs & Capps, 2001), typically involving one teller and reporting events whose tellability is more or less shared and guaranteed"* (Giaxoglou: 2015, 101).

But in light of the analysis presented in this chapter, three concerns can be raised in relation to the idea that this type of existential storytelling on social media is potentially more 'polished' or 'traditional': 1) The seemingly 'polished' storyline focused on moving from diagnosis to treatment to cure emerges more effectively if you read Janne's profile continuously and omit the comments; it is less clear if you, as intended, follow her communication in posts and comments on a daily basis where the storyline is sometimes lost, diverted or forgotten in the flow of everyday posting. 2) Platform logics and algorithms are furthermore crucial players in terms of 'curating' (Fernandes: 2017) what comes visible and invisible, to whom on the platform and thus inherently disturb the idea of a large coherent storyline presented to an audience of followers as parts of the storyline might simply 'disappear' from the personalized feed of specific readers. 3) Lastly, Janne's story is not only narrated by her but constantly acknowledged by and co-constructed with her followers through processes of ritual appreciation and supportive disalignment. Her followers are likewise explicitly invited to co-decide which type of narrative content should be articulated after Janne's cure. This interaction underlines, that the posts shared by Janne do not comprise a 'big story' in any traditional sense. The story's perceived (polished) coherence simply relies on a particular form of (unlikely and unintended) reading, and the profile's overall narrative – which might appear as 'individually told' when read post-to-post from beginning to end, is actually the result of daily social interactions with followers.

The case study presented in this article shows, that social media platforms are able to form publics of existential and affective support (Lagerkvist: 2017; Peters: 2015) or more critically a public focused on progress, positivity and vital patienthood (Rose: 2006; Stacey: 1997). This public of followers should not be understood as a passive audience witnessing an individual telling 'her own story' but rather as crucial contributors to the social interaction and co-creation of desired narratives, subject positions, narrative progress, and tellability. The platforms used are not simply channels for personal expression but also computational machines curating content in particular and often opaque ways. As such, despite the disease being biologically connected to the individual body, cancer storytelling on social media emerges through inherently social and mediated processes of reading, liking, commenting, monitoring, curating and co-deciding narrative practices.

References

Abidin, C. (2016). »Aren't These Just Young, Rich Women Doing Vain Things Online?«: Influencer Selfies as Subversive Frivolity. Social Media + Society, April-June, 1-17. https://doi.org/10.1177/2056305116641342

Ahmed, S. (2010). The Promise of Happiness. Durham: Duke University Press. https://doi.org/10.1215/9780822392781

Andersson, Y. (2017). Blogs and the Art of Dying: Blogging With, and About, Severe Cancer in Late Modern Swedish Society. OMEGA, 1-20. https://doi.org/10.1177/0030222817719806

Bamberg, M. (2006). Stories: Big or small: Why do we care? Narrative Inquiry, 16, 139-147. https://doi.org/10.1075/ni.16.1.18bam

Bamberg, M. (2016). Narrative. In K.B. Jensen, & T.T. Craig (Eds.), The International Encyclopedia of communication theory and philosophy Oxford: John Wiley & Sons, Inc. https://doi.org/10.1002/9781118766804.wbiect175

Bamberg, M., & Georgakopoulou, A. (2008). Small Stories as a New Perspective in Narrative and Identity Analysis. Text & Talk, 28, 377-396. https://doi.org/10.1515/TEXT.2008.018

boyd, d. (2011). Social Network Sites as Networked Publics: Affordances, Dynamics, and Implications. In Z. Papacharissi (Ed.), Networked Self: Identity, Community, and Culture on Social Network Sites. New York: Routledge.

Bury, M. (1982). Chronic Illness as biographical disruption. Sociology of Health and Illness, 2, 167-182. https://doi.org/10.1111/1467-9566.ep11339939

Charon, R. (2006). Narrative medicine. Honoring the stories of illness. New York: Oxford University Press.

Coll-Planas, G., & Visa, M. (2016). The wounded blogger: analysis of narratives by women with breast cancer. Sociology of Health and Illness, 38, 884-898. https://doi.org/10.1111/1467-9566.12405

Couser, G.T. (2016). Body Language: Illness, Disability, and Life Writing. Life writing, 13, 3-10. https://doi.org/10.1080/14484528.2016.1132376

Ess, C., & AoIR ethics working committee. (2002). Ethical decision-making and internet research. Recommendations from the aoir ethics working committee. AoIR.

Fernandes, S. (2017). Curated Stories: The Uses and Misuses of Storytelling. Oxford: Oxford University Press. https://doi.org/10.1093/acprof:oso/9780190618049.003.0001

Frank, A.W. (1995). The Wounded Storyteller. Chicago: Chicago University Press. https://doi.org/10.7208/chicago/9780226260037.001.0001

Freeman, M. (2006). Life »on holiday«?: In defense of big stories. Narrative Inquiry, 16, 131-138. https://doi.org/10.1075/ni.16.1.17fre

Georgakopoulou, A. (2006). Thinking big with small stories in narrative and identity analysis. Narrative Inquiry, 16, 122-130. https://doi.org/10.1075/ni.16.1.16geo

Georgakopoulou, A. (2016a). 'Friendly' Comments. Interactional Displays of Alignment on Facebook and YouTube. In S. Leppanen, S. Kytola, & E. Westinen (Eds.), Discourse and identification: diversity and heterogeneity in social media practices. New York: Routledge.

Georgakopoulou, A. (2016b). From narrating the self to posting self(ies): A small stories approach to selfies. Open Linguistics, 2, 300-317. https://doi.org/10.1515/opli-2016-0014

Georgakopoulou, A. (2016c). Small Stories Research: A Narrative Paradigm for the Analysis of Social Media. In L. Sloan, & A. Quan-Haase (Eds.), The Sage Handbook of Social Media Research Methods. London: Sage. https://doi.org/10.4135/9781473983847.n17

Giaxoglou, K. (2015). Entextualising mourning on Facebook: stories of grief as acts of sharing. New Review of Hypermedia and Multimedia, 21, 87-105. https://doi.org/10.1080/13614568.2014.983560

Hawkins, A.H. (1999). Reconstructing illness. Studies in Pathography. West Lafayette: Purdue University Press.

Heilferty, C. (2018). The Search for Balance: Prolonged Uncertainty in Parent Blogs of Childhood Cancer. Journal of Family Nursing, 1-21.

Ibrahim, Y. (2015). Instagramming life: banal imaging and the poetics of the everyday. Journal of Media Practice, 16, 42-54. https://doi.org/10.1080/14682753.2015.1015800

Jurecic, A. (2012). Illness as narrative. Pittsburgh: University of Pittsburgh Press. https://doi.org/10.2307/j.ctt5hjr8p

Kaplan, A., & Haenlein, M. (2010). Users of the world, unite! The challenges and opportunities of Social Media. Business Horizons, 53, 59-68. https://doi.org/10.1016/j.bushor.2009.09.003

Klastrup, L. (2016). Sociale netværksmedier. København: Samfundslitteratur.

Knudsen, B.T., & Stage, C. (2012). Online War Memorials. Memory Studies, 6, 418-436. https://doi.org/10.1177/1750698012458309

Labov, W., & Waletsky, J. (1967). Narrative analysis: Oral versions of personal experience. In J. Helm (Ed.), Proceedings of the 1966 Annual Spring Meeting of the American Ethnological Society. London/Seattle: University of Washington Press.

Lagerkvist, A. (2017). Existential media: Toward a theorization of digital thrownness. New Media and Society, 19, 96-110. https://doi.org/10.1177/1461444816649921

Lobinger, K. (2016). Photographs as things - photographs of things. A texto-material perspective on photo-sharing practices. Information, Communication & Society, 19, 475-488. https://doi.org/10.1080/1369118X.2015.1077262

Markham, A., & Buchanan, E. (2012). Ethical decision-making and internet research. Recommendations from the aoir ethics working committee (Version 2.0). AoIR.

Marwick, A. (2015). Instafame: Luxury Selfies in the Attention Economy. Public Culture, 27, 137-160. https://doi.org/10.1215/08992363-2798379

McCosker, A. (2013). Intensive Media: Aversive Affects and Visual Culture. Basingstoke: Palgrave. https://doi.org/10.1057/9781137273512

Nesby, L., & Salamonsen, A. (2016). Youth blogging and serious illness. Med Humanit, 42, 46-51. https://doi.org/10.1136/medhum-2015-010723

Ochs, E., & Capps, L. (2002). Living Narrative. Creating Lives in Everyday Storytelling. Cambridge: Harvard University Press.

Orgad, S. (2005). Storytelling Online. Talking Breast Cancer on the Internet. New York: Peter Lang.

Page, R. (2012). Stories and social media. Identities and interaction. New York: Routledge. https://doi.org/10.4324/9780203148617

Peters, J.D. (2015). The Marvelous Clouds. Chicago: Chicago University Press. https://doi.org/10.7208/chicago/9780226253978.001.0001

Phillips, W. (2011). LOLing at tragedy: Facebook trolls, memorial pages and resistance to grief online. First Monday, 16. https://doi.org/10.5210/fm.v16i12.3168

Pitts, V. (2004). Illness and Internet Empowerment: Writing and Reading Breast Cancer in Cyberspace. Health, 8, 33-59. https://doi.org/10.1177/1363459304038794

Rose, N. (2006). The Politics of Life Itself. Biomedicine, Power, and Subjectivity in the Twenty-First Century. Princeton: Princeton University Press. https://doi.org/10.1515/9781400827503

Seale, C. (2002). Cancer Heroics: A Study of News Reports with Particular Reference to Gender. Sociology, 36, 107-126. https://doi.org/10.1177/0038038502036001006

Sontag, S. (1991). Illness as metaphor. London: Penguin Books.

Stacey, J. (1997). Teratologies. A cultural study of cancer. London: Routledge.

Stage, C. (2017). Networked cancer. Affect, narrative and measurement. Basingstoke: Palgrave. https://doi.org/10.1007/978-3-319-51418-5

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Bogkapitel: Macintyre, S., & Ellaway, A. (2000). Ecological approaches: Rediscovering the role of the physical and social environment. In L. F. Berkman, & I. Kawachi (Eds.), Social epidemiology (pp. 332-348). New York: Oxford University Press.

Artikel: Cheek, J. (2004). At the Margins? Discourse analysis and qualitative research. Qualitative Health Research, 14, 1140–1150. doi: 10.1177/1049732304266820.

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