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Introducing patient stories in health sciences education: the learning experiences of students

Astrid Janssens[1,2,3*], Kirsten Børgesen[2,3], Anne Kragh-Sørensen[2,3], Janni Lykke Jensen[2,3], Henrik Nürnberg[2,3] and Bente Hoeck[4,5]

Abstract

Background It has been advocated that the development of medical school curricula must be informed by students, doctors in training, educators, employers, other health and social care professionals and patients, families and carers. Patients are widely employed to teach clinical and interpersonal skills, and while recognised as crucial in health education, they have mostly been offered a passive role. We assessed the impact of patients contributing personal illness narratives in the master curriculum of allied health care professionals on students' learning experiences.

Methods We designed a module (Patient and Society) for a master's degree programme in Health Sciences at the University of Southern Denmark in collaboration with six patients. The patients contributed to the teaching by sharing and discussing their personal illness narrative. At the end of the module, as part of the exam, we asked the students to reflect on the patients' contribution to the module and how this affected their learning experiences. The 500-word exam responses of 29 students were analysed, in collaboration with six patients, using thematic analysis.

Results Including patients' illness narratives lifted students' academic learning, and their personal and professional development. The stories brought theoretical concepts to life; it helped the students to obtain, retain, and apply academic knowledge. Actively and uninterrupted listening to patients' illness experiences promoted empathy and critical reflection on clinical practice. Faced with the impact of a disease on a person's life, seeing the healthcare system through a patient's lens made students reflect critically on the medical positivist model ruling the health care system focused on *just* fixing the medical problem with very little room for the illness experience.

Conclusion Our analyses support previous findings indicating that patient narratives are a powerful tool to achieve academic and professional development. Working with patients in health education has the potential to work towards a more inclusive epistemological stance in the health care system and health research.

Keywords Patient involvement, Health science education, Patient stories, Illness narratives, Co-production

*Correspondence:
Astrid Janssens
a.v.a.janssens-14@umcutrecht.nl
Full list of author information is available at the end of the article

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Background

Internationally, patient and public involvement in the design, conduct and dissemination of health research has become the new norm and a requirement for many funding organisations [1]. In Denmark, the process of collaborating with patients and relatives is yet to be formalised: the overall picture of involvement in health research is highly variable with some institutions carrying out extensive involvement and reporting significant impact, whilst others have only just started [2]. This shift towards active participation of patients and relatives in health research takes time and resources. Establishing a culture shift, whilst aiming for a sustainable change, requires action from different angles. Exposure to the 'phenomenon' of working with patients as partners in the health care system early in health care professionals' career is one way of initiating this shift [3].

Traditionally patients have been involved in the clinical curriculum of medical schools to teach clinical skills (e.g., physical examination, history-taking, and clinical reasoning) and interpersonal skills (e.g., communication skills). This has evolved to a more collaborative role for patients [4]. The involvement of patients in medical education has internationally been advocated for by organisations such as the UK's General Medical Council (2016) stating that "*the development of medical school curricula must be informed by medical students, doctors in training, educators, employers, other health and social care professionals and patients, families and carers*". The Danish Medical Association (Lægeforeningen) states that: "*The content of the specialist medical education is a medical responsibility*"; yet, the document mentions that "*the target descriptions are drawn up and revised in dialogue with relevant partners, including patients*" (authors' translation). Over the past decade, the active involvement of patients in education has expanded greatly: examples can now be found from basic training through postgraduate and continuing professional development. Two recent reviews showed a variety of patient involvement in medical education: patients sharing personal experiences with students, and patients involved in teaching and evaluating students [5, 6]. Most of the initiatives are introduced in medical education, but some come from nursing, social work, or multi-professional education. A review focusing on nursing students' clinical education explicated similar formats of involvement, comprising active contribution to students' learning, followers of care and advice, and learning platforms with whom students practiced their skills; yet concluded that the number of studies examining the involvement of real patients in students' education in clinical settings is very limited [7, 8].The benefits of students who engage with and learn from patients early in their education are numerous and include professional development, increased confidence and reduced stress when interacting with patients, development of self-reflection and appraisal skills, and professional identity development [9]. Educational experiences provided by patients are often more engaging and powerful which enhances memory, promotes empathy [10], and has a transformative capacity in the shift towards the coexistence of experiential and scientific biomedical knowledge [11]. The latter effect could assist in the participatory turn in health care and health research, where an epistemic divide hampers equal relationships in civic collaborative practices.

In Denmark, working with patients in an active role in health education is rare. Dijk et al.'s review identified one study reporting on patient involvement in medical education in Denmark, with patient instructors (patients with rheumatism) teaching health professionals and students in the context of combined faculty-led and patient-led teaching sessions [12].

This paper reports on the effects of the first step in the development of a systematic, institution-wide approach to establish patient involvement in health education at the University of Southern Denmark (SDU). This initiative is grounded in a democratic and emancipatory rationale for patient involvement: *a recognition of patient expertise as a legitimate source of knowledge that serves to move health professions education beyond the medical model* [13], p. 8). Following a change of module lead in 2019, we redesigned Patient and Society (in Danish, *Patient og Samfund*), a first semester module in the Master in Health Sciences, to be a fully patient-centred module. The curriculum as well as the delivery was overhauled and newly developed in collaboration with patients and students. Working with patients to develop and deliver the module served two objectives: 1) contribute to the learning objectives of the module and 2) initiate a shift towards patient-centred education. As such, the module should contribute to a sustainable change in health education and a culture shift in health care and research: shared power between patients and healthcare professionals and acceptance of all forms of knowledge.

A substantial change to the module was to include patients' narratives to the curriculum. As research is lacking on the use of patient narratives in health education [10], collecting evidence of the educational and pedagogic value of working with patients is crucial in making this a general, institutional approach to health education. Therefore, we evaluated the effect on students' learning of patients taking the role as teacher and sharing their illness narratives in a module of a master's degree programme in health science.

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Methods

Patient and student involvement in curriculum development and delivery

The module 'Patient and Society'

Patient and Society (*Patient og Samfund*) is a 10 ECTS point module taught in the first semester of the two-year Master in Health Science (Danish title: *sundhedsfaglige kandidatuddannelse*), at the Faculty of Health Sciences at the University of Southern Denmark (SDU). The master programme is rooted in theories and methods within health sciences, humanities, and social sciences; see Table 1 for the learning objectives as approved by SDU. The programme is multidisciplinary and provides an opportunity for immersion in, exploration of, and reflection on important areas within health professional practice and to develop health science competencies among health care professionals. Completion of the master's programme entitles the graduates to the title Master of Science in Health Science. In 2019, the first author was appointed module lead; this allowed for a complete overhaul of the module, including the learning objectives and content, and deliver a patient-centred module. Patients and students were invited to take part in this process.

The process of involving patients

The patient and relatives service (Patient og Pårørende-service) of Odense University Hospital (OUH) was approached to invite patients. This service maintains contact with approximately 45 hospital patients and patient relatives (friends or family members who provide care to a patient) who have signed up to be involved in infrastructure (e.g. design of a new hospital ward), research (e.g. selection of hospital funded PhD projects) and policy work (e.g. development of 5-year research strategy). In June 2019, they sent out an email to all patients and relatives signed up with the service with a request to contact AJ and BH if they were interested to share their illness story with students and to help with the development of the module. Seven patients (five women, two men) approached us; one patient withdrew before the first meeting – a retired male patient – due to a busy leisurely schedule. The six patients involved in year 1 of the module development had various illness experiences (e.g. different types of cancer, a liver condition) and were between 31 and 70 years of age.

Patients as educators on the module patient and society (2019)

In the months prior to the start of the new module (autumn 2019), the six patients were sent documents with a description of the module, description of the role of patient teacher on the module and their participation in the development of the module. As educators on the module, patients were asked to share their illness story during one of the 14 four-hour lectures. They were given a 30/40-min timeslot. They were free to choose how to bring their story. AJ and BH deliberately gave them as little instructions as possible to allow patients to deliver their story on their own terms. We did offer support when requested; for example, some wanted to deliver their narrative using a PowerPoint presentation, yet, felt ill equipped to do prepare this.

The process of involving students

At a two-day welcome event for new students, we had a 15-min slot to address students and invite them to take part in the development and evaluation of the module. As we received no reactions, the invite was repeated at the first lecture. Five female students volunteered; four students attended the first meeting. Due to the short (14-weeks) teaching period of this module, students found it difficult to stay connected as they had other academic obligations and finished their education after two years. One student has remained part of the panel until today.

The patient and society patient and student panel

Patients and students who had volunteered to assist in the development of the module formed the Patient and Society Patient and Student Panel (short: the panel). The purpose of the panel was to assist the module lead in shaping the learning objectives, content and delivery (e.g. teaching format) of the module. The panel met in September 2019, after the first lecture of the module. There was time for introductions and AJ and BH explained the

Table 1 Learning objectives of Patient and Society (2019–2022)

Knowledge	Skills	Competences
Explain key sociological, philosophical, and anthropological theories and concepts	Illustrate key theories and concepts using a contemporary health issue	Use two different theoretical perspectives to reflect on a health issue
Identify paradigms (theoretical frameworks) used in sociology, anthropology and philosophy	Analyse a contemporary health issue with a chosen concept or theory	Compare two theoretical perspectives on illness and disease

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role of the panel and presented the proposed content and learning objectives of the module.

Impact of patient stories on students' learning experiences: data collection

The module starts in September and runs for 8 weeks, with two four-hour sessions a week. At the end of the module, the learning objectives are assessed in an exam: a) essay on a given topic covering a main concept, 2) a portfolio, 3) short essay reflecting on learning related to the contribution of the six patients (see box 1). We included the latter question to evaluate the impact of patients' illness narratives on students' learning experiences. They were allowed to use up to 500 words to answer the two questions: 1) How did the patient contributions improve your learning? 2) How did it affect you (personally/professionally)?

The module lead provided an information package to all students ($n=67$) stating the purpose, risks, and benefits of the study. Students who agreed for their exams to be used as part of a research project evaluating the impact of patient teachers ($n=29$) signed an informed consent form stating that the data would be used for research purposes and reported in (amongst other) scientific publications including quotes assuring these would be anonymised such that they would remain unidentifiable.

Analysis process and team

All authors, including the patients and student of the panel, were part of the team performing the analysis; this enriched the process and enabled a multifaceted consideration of the data. AJ is a psychologist and anthropologist with over fifteen years of qualitative research experience in health services research and collaborating with patients and members of the public in health research. BH is a nurse with several years in practice followed by a turn to research activities focused on qualitative work related to nursing and caring science including both theoretical and clinical studies. The patients in the panel are or have been a patient and some also a carer to a patient at the Odense University Hospital (OUH, Denmark). Most of them had experience of being involved in research councils and committees at the hospital, where they for example reviewed and assessed research proposals.

Due to COVID-19 restrictions, we were not allowed to meet at university premises. Fulfilling the necessary administrative and technical requirements to access and analyse study data (using specific software) from home was too challenging for patients. Instead, they were given anonymised exams and were involved in the analytical process through online group discussions.

Data analysis

The explorative nature of the study and focused data generation guided us towards an inductive thematic analysis [14]; an explorative thematic analysis allowed patients to work with the exams without extensive training in analytical methods and made it easy for the patients to fully engage with the analysis. AJ and BH read the 29 exams, generated initial codes, and discussed initial identified patterns. AJ and BH coded the exams, using NVivo software version 12 (QSR International Pty Ltd., Doncaster, VIC, Australia), to "explore the diversity and patterning of meaning from the dataset, developing codes, and applying code labels to specific segments of each data item" ([15], pg. 53). The patients were given a random selection of six exams; each patient received three exams that were also allocated to someone else, and three exams that were solely allocated to them. As such, all exams were read by at least one patient, in addition to the researchers. They were asked a) what they 'learned from the answers of the students?' and b) to extract from the exams 'elements that surprised you'. Two weeks before the first panel meeting on the qualitative analysis, they received a document with a presentation of the preliminary analysis conducted by AJ and BH. The document presented identified repeated patterns—presented as *groups (themes)*—including all underlying codes, illustrated with relevant quotes. At an online Zoom-meeting AJ and BH presented the preliminary analysis. The following questions were used at different analysis meetings to assist patients' contributions: 'did you identify learning impact that we have not reported'; 'when you read the exams and recollect how you experienced this teaching: What hit you the most?', 'thinking about your contribution to teaching on this module, what do you learn from the results of this study?'; and follow-up questions such as 'did you pick up on things that we have not seen, or have not mentioned?'. We had several meetings with the team (including patients and researchers) discussing the data and our interpretations. During these meetings, patterns of meaning were identified. The codes and themes were no longer captured in NVivo; AJ and BH used Microsoft Word to write up the evolution of the themes after each group meeting to reflect the panel's contribution. The findings as reported here (e.g. selection of quotes, names of themes) are the co-constructed findings, and the result of discussions with the patients throughout the writing process.

Ethical considerations

The project is registered for legal and GDPR concerns by the University of Southern Denmark, journal number: 10.628. According to Danish law, no ethics approval is needed for this type of study [16]. We conducted the

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research following the Danish Code of Conduct for Research Integrity [17] and in accordance with the Helsinki Declaration.

All exams are anonymous to assessors. All students were invited to participate in this study; they were informed about the purpose, risks, and benefits of the study via an information package. Those students who approved for their exams to be included in this study, signed an informed consent form stating that the data would be used for research purposes and reported in (amongst other) scientific publications including quotes assuring these would be anonymised such that they would remain unidentifiable.

In line with GDPR and university guidelines we describe the student population in generic terms. The quotes are reported with reference to an anonymised number (1–29) to illustrate the diversity of selected quotes; the link between anonymised number and SDU student number is stored on a secured server and can be checked upon request.

Results

In 2019, a total of 67 students were registered for the Master of Health Sciences at SDU; four of those were men. The average age of students was 30,2 years. The vast majority of students had a background in nursing, followed by physiotherapists and students with a professional bachelor in nutrition or health professions (midwife, occupational therapists and radiographer). A total of 29 students consented to have their exams included in this study.

Overall, the patients' contributions to the module were welcomed by the students; they were evaluated as an *enriching experience, an exciting supplement to the ordinary lessons* and *a good tool to improve learning.* The students' reflections showed that the patient stories had effect beyond the mere educational domain. The three themes, presented in Table 2, were created to reflect the different domains that appeared in the students' reflections: 1) the educational domain with a focus on the pedagogical value of patient stories; 2) the personal domain with the (unexpected) emotional impact of narratives on students; and 3) the professional domain with patient stories forcing students to critically reflect on their (former or future) work environment.

Stories as vehicles for learning

The students explain in their exams *how* – through different forms and ways—the narratives have contributed to their learning: learning through repetition, learning through reflecting, using stories as examples of concepts and theories taught in the module, learning by meaning

making of the stories, applying theoretical knowledge to patient stories, and linking theories to practice.

a) A layered learning process with repeated exposure: diverse repeated exposure to module content

The narrative nature of the patients' contribution in the module created a layered learning process. The stories invited students to *work* with the content in different ways: listening, reflecting on the stories, processing the events narrated, the meaning making in discussions with peers, and relating the stories to the theories and concepts taught in the module. The patient stories allowed for various diverse ways of dealing with the module content, and thus resulted in extended exposure to the module's concepts and theories.

My learning has been threefold. The learning consisted of listening to Patient X's story, discussing it with a fellow student, and finally immersing myself in the episode of this exam paper (Student 5).

The patients were scheduled at different weeks of the 8-week module. This allowed for gradual *unfolding* of the stories. Concepts and theories that had been taught prior to a patient's story could be applied immediately to the stories, whereas theories or concepts taught later were retrogradely being applied to stories told revealing different insights.

When I hear the narratives, I can pick bits from the stories that fit the topic of the week. But as I learn new topics, I can also look back at previous narratives and link these narratives to the newly acquired theoretical concepts (Student 21).

b) Deepening understanding of concepts and theories taught in the module

Students explained that the stories triggered learned concepts and theories; this strengthened (any) previous learning. It also showed the power of concepts and theories in *understanding* what unfolded in front of them. The patient stories made the theories and concepts explored in the module tangible, concrete, and thus more relevant and applicable in their (future) professional life.

For example, when Patient Q was telling her story, she evoked learning of Frank's explanation of narrative templates. Arthur Frank identifies three core narrative templates in which stories about illness can be told. [the student continues and explains how the story of one of the patients matched with one of Arthur Frank's narrative typology [18]] (Student 29).

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Table 2 Overview of themes, subthemes, and illustrative quotes

Educational domain	Stories as vehicles for learning
	A layered learning process with repeated exposure
	At first it was hard to specify how these narratives were helpful for my learning process, so during the presentations I primarily sat and listened to the patient's story as I would have done if I was at work. Afterwards the reflection began, and I started to consider how different these patients were (Student 1)
	The patient narratives were distributed throughout the module, allowing me to continuously relate them to newly learned theories, this results in a form of repetition of the theories (Student 19)
	Deepening understanding of concepts and theories taught in the module
	The narrative supported my learning by emphasizing that this disease—illness distinction seems more evident than just a theoretical concept (Student 1)
	They [the patients] brought the concepts to life and made the theories easier to understand and translate into more real-life learning, transferable to my daily work in health care (Student 22)
	They were a reminder that what we learn applies to patients in real life and isn't just a theory that can be used in an exam (Student 16)
	The patient contribution allows me to reflect on the theory and content and relate it to the real world which takes place in the healthcare system (Student 26)
	Learning how to process patient (experiential) knowledge
	At first, I didn't know where to focus when listening to the stories (Student 22)
Personal domain	The emotional experience: empathy for and being inspired by patients
	Empathy: feeling patients' pain and wrongdoing by the health care system
	In addition, Patient Y says that in the encounter with strangers, an awkward mood often arises when she says that she has cancer. It makes a deep impression on me that in 2019 there is still a hint of anxiety around the word cancer (Student 12)
	Humbled and inspired by the strength of the patients
	If I met Patient Q on the street, I would have no idea how sick she is. One cannot help but be impressed by her energy and positive upbeat approach to presenting her story to us as well as to the course itself (Student 15)
Professional domain	The patient stories: a window for reflection on professional practice
	The patient perspective: humanising the patient again
	It made an impression on me how much a diagnose fills a human's life and how it can have an impact on the illness experience. To hear the patients' narratives has shown me exactly how complex the terms illness and disease really are (Student 26)
	Through first-hand narratives, I have heard how patients are subjectively experiencing illness. Not only when they identify themselves as patients, but also as family members, employees, etc. (Student 16)
	Critical reflection on the health care system and a calling to do things differently
	She says at one point that she can never plan anything since she never knows what date and what time of the day, she will suddenly receive a new call from the hospital. It makes me think about how resourceful we assume patients to be. It takes a lot to be sick in today's Denmark (Student 15)
	A few of the patients told us that they don't need more time rather they want the professionals to act differently in their interactions. This was one of the things that had the greatest impact on me, that I can do something, without spending more time but only by changing the way I perceive and meet people (Student 8)
	Patient V suggests the nurse walking past him in the waiting room, but he does not experience being seen. The concept of care has started to down on me. Care is not about how much time you have or what you can or should achieve. Going forward, I want to think more closely about the quality of care and being present. The eye contact that Patient V seeks, does not cost extra time, but precisely helps to show closeness and care (Student 27)

In their exams, the students gave examples that illustrated how the stories contributed to dealing with concepts and theories taught in the module: they used the stories to explain the concepts or applied theories and concepts to the patient stories to make meaning of the stories. Students gave numerous such examples to illustrate how the stories had helped them to understand and apply the theories.

> *According to Arthur Frank there are three narrative types: restitution, chaos, and quest. It was interesting to see how these types were in present in the patient narratives [18] (Student 26).*

In addition to obtaining and retaining knowledge, the stories thus contributed to more complex cognitive processes (or skills), such as exemplifying theories taught in the module with the stories and applying concepts to empirical data.

> *It developed my ability to identify and apply the concepts and theories to real-life-stories which complement the learning from reading, lectures, and student presentations. My ability to analyse and interpret patient narratives and place them in a theoretical and/or societal perspective was optimized (Student 1).*

This student explains how the stories illustrated the relevance of the theories and concepts for their clinical practice:

> *When I first heard the story [of Patient x], I was primarily personally influenced, but as I got further*

into the subject and learned more theory whilst progressing in the module, I tried to gain a theoretical understanding of why the episode affected Patient X as it did (Student 9).

c) Learning how to process patient (experiential) knowledge

Our experiences (of both teachers and patients) during the lectures were confirmed reading the exams: initially, students were confused by the patient stories. They had a hard time processing the stories as *knowledge*; patient experiences are not presented in a standard fixed format. They didn't know how to take notes and learn from these stories. On one hand students acknowledged the importance of patients' experiential knowledge whilst also expressing unfamiliarity with the unstructured experiential learning and scepticism regarding the useability of patient *knowledge*:

It was hard to specify how these narratives were helpful for my learning process, so during the presentations I primarily sat and listened to the patient's story. Afterwards the reflection began, and I started to consider how different these patients were (Student 1).

The emotional experience: empathy for and being inspired by patients
The students are somehow caught off-guard. They are aware that in their (future) role of health care professional they will be exposed to such stories and are armed with their clinical uniform. The lecture theatre, the educational setting with the patient taking front stage, created a different experience; it allowed for time to listen and reflect, and allowed for emotions to be felt and processed.

a) Empathy: feeling patients' pain and wrongdoing by the health care system

Students explained in their exams that their first reaction to the stories was a deep emotional reaction. This reaction was provoked by the content of the stories and witnessing empowered patients sharing their story—uninterrupted—in front of a large group. This made a big and lasting impression on them:

It evoked something in me, it touched me personally. [...] The pain patient Y is experiencing, hurts me deep inside (Student 14).

During my career, I've cared for many patients in similar situations, and as a nurse, I'm trained to embrace empathy and professional sympathy. There was however a slightly strengthened impact by hearing the narrative outside of a clinical setting (Student 6).

The stories told, as some students mentioned, might not be new, but the students are *forced* to hear them and listen as a human, not as a nurse, dietician, midwife, physiotherapist, occupational therapists, or radiographer.

As a clinician with many years of experience, I have heard many medical stories, but in this format, we gain a deep understanding of the individual's very personal experience of the disease's impact on his own body and soul (Student 23).

b) Humbled and inspired by the strength of the patients

Students praise the patients for contributing to the teaching, sharing their intimate feelings and experiences, their bravery, and strength in how they deal with everyday life during or in the aftermath of a life-changing illness.

I am touched to hear how the illness and the intensive treatment continue to adversely affect her life, but also about how Patient C is able to create new meaning and hope in such a markedly changed life situation (Student 17).

The stories made the students reflect on their own life and behaviour. These stories affected some personally and made them *"even more grateful for my good health than I was before"* (Student 9). Students described the patients as a source of inspiration, demonstrating various coping strategies, and were filled with hope *"that if one is himself affected by illness, it does not mean that one's life is not worth living"* (Student 17).

The patient stories: a window for reflection on professional practice
The patient stories offered two new insights: how a disease is experienced by a patient (the illness experience) and how patients perceive the health care system. Both these insights provoked reflection on practice in the health care system and generated ideas for change.

a) The patient perspective: Humanising the patient again

Many students mentioned that the patients' stories illustrated how *illness* is much more than disease. These

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two concepts are key concepts in the module and dealt with throughout the module, whereby phenomenology is mentioned as an approach to understand the personal experience of disease (illness). Yet, the patient narratives made them see the person that is the patient. The students mention that it were the stories that enabled a deeper understanding of patients' experiences of being ill and the importance of knowing these experiences (as a healthcare professional).

> *These stories made me realise how important it is to understand the individual's life and their experiences (Student 15).*
> *The stories gave me a more nuanced picture of what you as a patient can experience and feel, in your encounter with the healthcare system (Student 10).*

Some students stated in their essays that hearing the stories made these patients 'human' again; it made them see these people as more than 'just' patients. The students showed an altered perception or awareness of patients' illness experiences and a new experience of patients' feelings. This has made big impression on students, and for many they were a reminder of what attending to patients' needs should be about:

> *I feel my perception on the human standing in front of me changing. I see the human instead of just a patient (Student 13).*
> *But after all, how far have we come when the patient narratives paint a picture of patients who are still turned into excel sheets and not included in their treatment? It has motivated me to look more critically at daily practice and more often ask the question: Is it for the system's or the patient's sake? Not least, it has inspired me to work towards changing this practice (Student 22).*

b) Critical reflection on the health care system and a calling to do things differently

In their exams, students refer to the patients' illness experiences as the *subjective experience*. These reflections illustrate that the students are anchored in a positivistic approach. Some students acknowledge this preoccupation with the biomedical model of health and question the actions or decisions of health care professionals featuring in the patients' stories:

> *For the health professional, the task is finished when the treatment is completed. However, the physician could have shown a greater understanding of Patient A and how illness and treatment affected her life – like in the Logic of Care [19] (Student 17).*

Another element that struck students was health care professionals' strong focus on *curing* and the bio-medically inspired restitution narrative [20]. They were amazed by their own focus on fixing problems and not allowing patients to *sit within the chaos* [18] caused by their condition:

> *A young woman, Y, told 'a chaos narrative' about her ongoing course of illness with malignant melanoma. I was struck personally because we are the same age, but also professionally, because I became aware of how important it is to stay in the chaos narrative and not try to fix the chaos that Frank [18] describes. This I will take with me the next time I meet a family who is in the middle of a chaos narrative (Student 2).*

The combination of uninterrupted listening and empathising with the patients outside of the health care arena has triggered critical reflection on clinical practice, the organisation of the health care system, and its impact on patients. Some students shared that the stories had made them reflect on their own (past) professional behaviour, which might have been perceived as painful and harmful:

> *Sometimes, I meet people with humour. This is perhaps to protect myself and somehow the patients as well. I don't think we are always aware of the patients and their situation. Are they in a place where humour is okay? I think this is about connecting with the patients, and this can be difficult. Patient X seems like a humorous and down-to-earth man, but both his friend, who knew him well, and the doctor, read him wrong (Student 10).*

They *feel* the patients' pain and wrongdoing inflicted by the health care system and question the practice of the current health care system, and who's needs it serves:

> *In the stories, consequences of treatments such as incontinence, memory difficulties, loss of senses (e.g. smell), etc. were very present and important in patients' everyday lives. According to one patient, the health professionals' definition of 'being healthy' did not match with the side effects she was still experiencing. This initiated reflections, as I provide chemotherapy aimed at getting children healthy, but we don't see what they want for the rest of their lives (Student 16).*

Students picked up many stressors and poor experiences patients had in their clinical interactions. They openly questioned how hard it is to be a patient and how the health care system adds to the suffering of patients in many ways:

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Being a nurse for 25 years, working in a system which is highly influenced by the biomedical model, that deals with patients as machines and therefore acts with a certain view of how patients are regarded and treated, made me reflect on how it is to be a patient in today's health care system. It made me reflect on how vulnerable it is to be a patient in the Danish health care system and how hard it is to navigate this system, getting ones everyday-life to fit into the system (Student 13).

These stories have been an eye-opener for many of the students: *"I am rebelliously inspired and ready to think innovatively. I will allow myself to be inspired in education along the way" (Student 19)*. Students deepened their reflections and suggested changes feasible for them to put in practice. Some referred to a personal calling to make a difference. Students vowed to have more attention to the illness experience of patients, or treating both disease and illness, and focus on care as well as cure.

Patient A's story indicates that our health system is build up around the biomedical version with a focus on disease, which I recognize in my current profession. I work at a neonatal unit, where much of the nursing consist of practical procedures and sometimes, we forget the parent's and the illness they can feel, having a sick or preterm infant. I will definitely - after the patient contribution and the knowledge I have gained - have more focus on both treating disease and illness (Student 26).

Taking the time to listen to a patient tell their story even for a short amount of time and in the unfocused moments of mundane medical practice is what I will try reminding myself to do, to get the wider patient experience (Student 29).

Interpretation and discussion of findings
This paper describes the early steps of collaborating with patients in health education curriculum design and reports on the effect on students' learning. We asked students to reflect on their learning, in relation to patient illness stories shared during lectures of a module in the master of health science. The learning experiences narrated by the students in their exam essays showed parallels with previously reported learning outcomes of health education programmes with patient educators [5] or patient narratives [21, 22]. Our students reported that the patient stories improved their understanding of concepts and theories taught; it offered them relevant concrete examples and a way to engage with the material. These benefits echo the theoretical benefits of narratives described in the literature [10, 23]. The stories served a pedagogical purpose; they enabled students to develop a deeper understanding of certain theories and concepts

[24, 25], and helped to close the gap between patient experiences and the theories used to understand them. Different to previous work using patient stories, we used six patient stories as a framework to undergird an entire course. Therefore, the interaction between theoretical knowledge (key theories and concepts of the module) and patient narratives worked both ways: the stories triggered certain theories and concepts, but as the students' theoretical knowledge increased throughout the module, they used this knowledge to gain a better understanding of the patients' illness experiences. Students also reported on the emotional impact of the stories. The emotionally charged nature of stories enhances learning [26] as well as personal and professional reflection.

From an academic, educational angle, the students benefited on several of Bloom's educational objectives: knowledge acquisition, understanding, application of knowledge, and analysis as a result of the patient illness stories [27]. In addition to contributing to the learning objectives of the module, we introduced patients as educators to challenge the prevalent positivist approach in medical settings and embrace patient experiences as valid knowledge. The students reported that the patient stories challenged their worldview, their own assumptions, and their professional reference model, and commanded to consider multiple perspectives. We cannot claim that they have embraced patient stories as a valid source of knowledge. However, listening, reflecting, and working with the patient stories offered the students a different experience of disease—namely *illness*, and broadened their perception and understanding of disease. It allowed time to listen to patients' experiences and created a sense of personal growth. These learning outcomes could be mapped to level 2 of Kirkpatrick' model for assessing the effectiveness of programs in higher education [28]: modifications of attitudes or perceptions. A review by Milota et al. mentions several studies that reported improvements on level 2 where students showed an increased sense of empathy for and connection with their patients following narrative medicine course [9].

Most of the students in the master programme have worked as or are still active as health care professionals (nurses, physiotherapists, dietitians, occupational therapists, psychologists) and have patient encounters in their daily practice. However, the patients presenting their story, untriggered and uninterrupted by health care professionals' questions targeted at gathering medically relevant information outside the clinical setting was a new experience and at times confrontational. The patient stories had added value to students with and without prior work experience in the health care system. In their essays, students questioned the predominant narrow focus on cure in healthcare and the lack

of humanity and sensitivity. Some students mentioned that these stories had instigated them to change their practice and actively fight the additional burden caused by the health care system. This is in concordance with international research demonstrating pedagogical benefits of narrative learning, particularly reflection on practice and promoting empathy [10, 26].

Our study showed that patients contribute with important, yet different aspects of disease, referred to as illness, than health care teachers and offer a unique insight in the health care system. These are important lessons to learn if we truly want to involve patient in (their) care. Our findings also showed that students with a professional bachelor and some years of work experience in the Danish health care system valued and benefited from experiential knowledge. This shows the potential and need of involving patients in teaching established health care professionals, for example in refresher courses and or any additional professional training.

The data collection and analysis in this study has some limitations. Only half of the students completing the module consented for their exam to be used for research purposes. AJ and BH read all the exams; they did not analyse the exams of non-consenting students but did not consider the learning experiences reported in those exams to differ from those reported by students included in the study.

Conclusion

The purpose of integrating patient experiences in the module Patient and Society in the master in health sciences was twofold: 1) to contribute to the learning objectives of the module and 2) initiate a shift towards patient-centred and patient-driven planning and delivery of the education of health professionals. The students' learning experiences illustrate a stronger and deeper learning of the material dealt with in the module whilst also offering a new perspective on the health care system. The patient narratives evoked empathy, inspired patient-centred care, encouraged self-reflection and compassion, and reinforced professional ethics. This study shows that patient narratives have the potential to improve educational practices in health education. Working with patients in health education helps to develop a culture of valuing and accepting different types of knowledge.

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12909-024-05987-x.

> Supplementary Material 1.

Declarations

Ethics approval and consent to participate
The project is registered for legal and GDPR concerns by the University of Southern Denmark, journal number: 10.628. Ethical approval is not required by Danish law for interview or text analysis [16]. The project follows The Danish Code of Conduct for Research Integrity and is carried out in accordance with the Helsinki Declaration. Potential participants were informed about the purpose, risks, and benefits of the study via an information package. The study participants signed an informed consent form stating that the data would be used for research purposes and reported in (amongst other) scientific publications including quotes assuring these would be anonymised such that they would remain unidentifiable.

Consent for publication
Not applicable.

Competing interests
The authors declare no competing interests.

Author details
[1]Utrecht University Medical Center, Utrecht University, Heidelberglaan 100, Huispost Nr. Stratenum 6.131, P.O. Box 85500, Utrecht, GA 3508, Netherlands. [2]User Perspectives and Community-Based Interventions, Department of Public Health, University of Southern Denmark, Niels Bohrs Alle 1, Odense 5230, Denmark. [3]Center for Research in Partnership With Patients and Relatives (ForSa-P), Odense University Hospital, Odense, Denmark. [4]Health Sciences Research Centre, University College Lillebaelt, Svendborg, Denmark. [5]Department of Public Health, University of Southern Denmark, Odense, Denmark.

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