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Stormy weather in healthcare: A new ecology

Jane Clemensen,^{1,2,3} Pernille Ravn Jakobsen,² Charlotte Myhre Jense,^{2,6} Kristina Garne Holm,^{1,3} and Mette Rothmann^{2,3,4,5}

Abstract

This paper discusses how the roles of patients and health professionals have changed over the years. It also explores how accelerated courses of treatment and busy staff have turned healthcare services and hospitals into “factories”, where care and relationships now exist in very cramped conditions. The paper discusses the gap between patients’ need for care and the care received. The analysis and discussion focus on how health professionals can be empowered to re-find care in their daily practice. We reveal how different health paradigms can affect care, and the relationship between patients and healthcare professionals, by a dominant paradigm. We suggest a shift in focus from valuing the neo-liberal approach, to focus on care by linking an Ecology of Care (EoC) approach to the healthcare context, as EoC can be used as a complementary philosophy to help change the paradigm and thereby secure a holistic approach to one another.

Keywords

Ecology of Care; Care; Participatory Design; Future Healthcare; New Hospitals, Change of Mindset.

Introduction

The Danish healthcare system is based on public welfare provision and decentralised welfare administration (Vrangbæk & Christiansen, 2005), as in many other Western

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countries. The entire society and thus also the healthcare system is organised as services based on neoliberal bureaucratic regulations and ideas (Holen & Ahrenkiel, 2011; Mik-Meyer & Villadsen, 2007); that is, political ideas based on minimising public costs, privatising as many welfare services as possible, and emphasising individual freedom, especially in acting and exercising one's choice freely (Glasdam et al., 2015).

Background

Developments, such as new super small hospitals that are replacing far bigger hospitals with more beds, have an inbuilt need to reorganise courses of treatment. Accelerated courses of treatment are increasing within all specialties (Moffatt, Martin, & Timmons, 2014). At the same time, due to broader economic pressures brought on by changing demographics, there is a general demand to minimise the expense of treatment (Weiner & Schwartz, 2015). This calls for a shift in paradigm – a shift that has already begun.

In tandem with these developments, the role of patients in terms of their own care is changing rapidly. A new, more active role is being pushed onto the individual by a healthcare sector that, through new technologies, is able to diagnose and treat more patients. At the same time, being a health professional often includes a close relationship with patients and relatives, in which care is one of the core values for a successful relationship. Accelerated courses of treatment, increased focus on data collection and risk aversion, plus very busy staff, has turned healthcare services and hospitals into “factories”, where care and relationships now exist in very cramped conditions.

Given this picture several questions emerge. Is it still possible to create a valuable relationship during the short meeting between staff and patient, or has the system overtaken the life of the patient? Can this gap be overcome by moving treatment and care to the homes of the patients through the use of technology? Are we overlooking important issues by pursuing better economies? And are we in fact creating a new gap – a gap between needs and capacity? Another issue at stake is the complex question of whether another gap is emerging in the healthcare system versus the system's strategies and its practice? And perhaps most importantly, how do we ensure care remains in our relationships with patients and their families? These questions are made more pressing by changes in the roles in healthcare, an area where patients and citizens demand involvement.

Aim

The aim of this paper is to discuss the gap between patients' need for care and the care received. The overall perspective is to discuss a new mindset for health professionals by empowering them to find and focus on the suppressed areas in their daily practice.

Theoretical framework

Care

The word “care” means “To have feelings like: concern, responsibility or love for someone or something”.² The United States psychologist Rollo May described care in regard to being a human being in this way: “When we do not care, we lose our being; and care is the way back to being”. Thus, being human is constituted in attitudes to care (May, 1969, p. 290).

In the book, *Nursing: The Practice of Caring*, Bishop and Scudder refer to Heidegger in explaining how care can be taken away in an attempt to provide care; in other words, it can be the opposite of care when someone “jumps in” and takes over for the other, who then is dominated and dependent in the caring relationship. Doing what the other can do for himself or herself, the “solicitous” person is actually taking “care” away from the other. In contrast, Heidegger says, there is a solicitous care that “jumps ahead” of the other, anticipating his or her potentiality not in order to take away “care” but to give it back (Bishop & Scudder, 1991).

John Gregory was a prominent Scottish physician-philosopher, who applied the ethics of “sympathy” and “humanity” to the medical care of the sick. Gregory held that the chief moral quality “peculiarly required in the character of a physician” is humanity; namely, “that sensibility of heart which makes us feel for the distresses of our fellow creatures, and which, of consequence, incites us in the most powerful manner to relieve them” (Gregory, 1817, p. 22). Moral quality paired with humanity is sympathy, which “produces an anxious attention to a thousand little circumstances that may tend to relieve the patient” and “naturally engages the affection and confidence of a patient, which, in many cases, is of the utmost consequence to his recovery” (Gregory, 1817, p. 22). The thousand little circumstances might be a way to describe and understand the nature of what Ian Coxon calls “an Ecology of Care” (EoC)³ and how complicated it is meeting your patient when he or she is in need of care and treatment.

Ian Hargraves, a researcher at the Mayo Clinic, has worked with Care in an EoC context. He maintains that the future of care in healthcare involves both honouring material conditions while developing the capacity to change those conditions and live well amongst them. At the same time that future must resist the temptation to insist that individuals alone are authors of their lives and that we are all in need of healthy relationships. Self-care must go beyond an insistence that individuals make something of themselves, to recognition that it is in relationship and community that people breathe life into one another. The future of care in healthcare is not the power of healthcare to shape human lives, but rather the shaping of our institutions, disciplines,

² www.yourdictionary.com

³ All references to Ecology of Care come from the website of the Ecology of Care Network: <http://www.ecologyofcare.net>

and practices of care to remembering, raising and celebrating what is good in human life and living.⁴

Ecology of Care⁵

The EoC Network began as a research group based in the Faculty of Engineering at the University of Southern Denmark. Today it is a Community Interest Company (CIC) registered in the United Kingdom whose aim to network ideas and theories regarding development of the concept of EoC.

In Figure 1, Ian Coxon has illustrated EoC in relation to being human. To challenge this figure we, the authors of this paper, question the placement of “Ecology” and suggest it could be replaced with “Compassion”, since it is a core element in successful interaction with others. We would also take “Ecology” and create a circle around the “Human” illustrating everything’s connectivity.

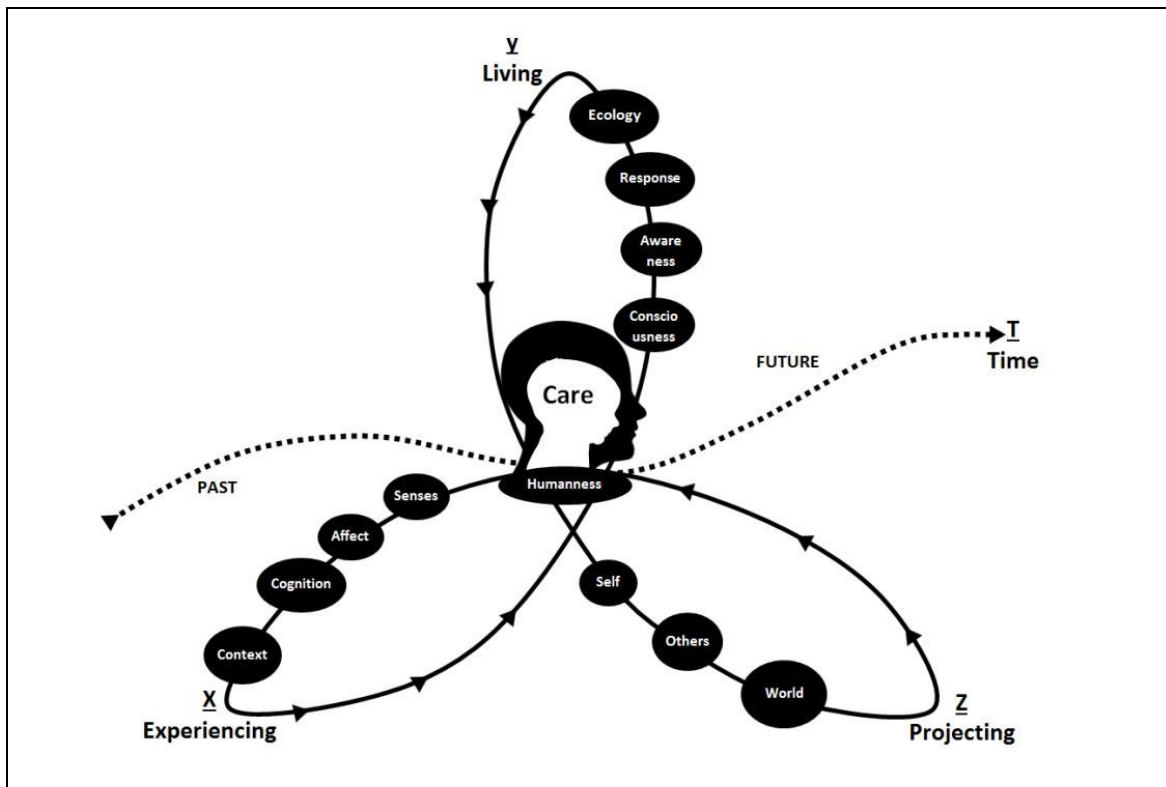


Figure 1. The Ecology of Care Model (developed for the 2015 EoC symposium).

⁵ This section draws on information from the EoC website and related material.

Ian Coxon describes the concept: “An Ecology of Care means Caring for our Home and everyone within it”. Freely translated into the context of healthcare, EoC establishes that the patient belongs to “a home” including everything and everyone that belongs to it – next of kin, pets, parents, neighbours, the shelter you live in, your economy, your job and education, and so on. When treatment is needed, the healthcare system tends to focus solely on the symptoms. Hence, the system does not take important matters from the patient’s daily life into account – things that might be the cause of the illness or affect the treatment and care around it. Today’s healthcare system is divided into pillars/sectors, each monitoring and addressing what is considered to be its own area of responsibility; therefore, it tends to ignore a holistic approach.

From Health 1.0 to Health 3.0

One way of describing the development and the belonging paradigms in healthcare is the evolution from Health 1.0 to Health 3.0. Characteristic of the Health 1.0 area were the defined roles between healthcare staff and patients. The doctor was the unquestionable expert and authority while the patient was passive, waiting for the doctor solely to decide treatment and regimes. Nursing and other staff were functional assistants to the doctors’ domain, and care was still the duty of the nursing group. When admitted to hospital, the patient was placed in a bed and the body was treated. At the same time, nursing staff also focused on creating a relationship with, and caring for, the individual. It is also important to note that the role of the patients’ relatives was not yet defined and included in health services.

Health 2.0 might be the area we still belong to (possibly with a foot in both Health 1.0 and Health 3.0 depending on the culture and the persons who provide the care). In Health 2.0 we discover more active and responsible patients who collaborate with staff and do not necessarily accept the experts’ advice. Technology is used for self-monitoring and self-diagnosis. Blood pressure, weight, steps and sporting activities are captured on mobile/cell phones and shared with networks (Steele, 2014). New technologies empower individuals and new knowledge is created and shared in new ways, intruding more and more on professionals carrying out their work. A good example of how patients share knowledge and use the new common knowledge in negotiating with experts is the website *patientslikeme*.⁶

In Health 3.0 the focus is moving from the individual to an attempt to capture the health ecosystem, including both mental and physical health and wellbeing. The body and mind are no longer divided. Instead, the body and mind are increasingly connected and a holistic approach aims to create a “life balance”. There is a shift in roles between professionals, and patients and their relatives, and patients often consider themselves to be the experts. Hence, professionals are increasingly seen as coaches. In this context, knowledge will not only be shared but also often used in relation to research, and patients’ fears will be conquered by peer-to-peer education and coaching. Furthermore, patients and relatives themselves will participate in educational activities with staff and healthcare students. In this paradigm, patients in general will not be given

⁶ <https://www.patientslikeme.com>

responsibility but will take it as a natural matter-of-fact (Clemensen, Clemensen, Syse, Danbjørg, & Coxon, 2016; Gagnon & Chartier, 2012; Nash, 2008).

Exemplary cases as a basis for the discussion

For the last 14 years we, the authors, have conducted research together with our patients, their relatives and our staff using participatory design research method (Clemensen et al., 2007; Clemensen, Rothmann, Smith, Caffery, & Danbjørg, 2016). The findings from all of our studies show a gap between the hospital services and the needs and wishes of the patients and their relatives. Initially, the aim was to empower the patients to help them to improve quality-of-life but as time has gone by and experience increased we realised that we might need to start the empowering process somewhere else: namely, within the system, the management and the staff.

The following three cases are taken from our research.

Case 1: The need for care

A hip fracture is a serious injury, with complications that can be life threatening. A systematised guideline including rapid mobilisation was introduced as a tool for quality recovery and improvement of efficiency in pathways with a short stay in hospital. The aim of this case study was to describe the experience of patients with a hip fracture and explore if they felt empowered and able to perform self-care in pathways with a short stay in hospital.⁷ Field studies were conducted in hospitals and in patients' homes, and interviews were performed with patients, family members and health professionals.

In order to implement pathways with a reduced stay in hospital, the health professionals' in the hospital said that their tasks required standardised preparation with stringency and conformity. While the standardised and systematised pathway was described as effective by health professionals, patients felt they were not seen as human beings. Our study demonstrated that patients recovering from hip fractures have a strong desire to be in charge of their own lives and to remain autonomous. Acquiring a hip fracture is a reminder of the frailty of life. This stressful situation complicates the ability to comprehend and retain important information provided during treatment with a short stay in hospital. Our study challenged the conventional method of informing and educating patients in fast-track treatment as a means of recovery, and suggested that new and improved methods of communicating health knowledge and promoting and enabling patient-empowerment are required to support autonomy and self-care (Jensen et al., 2017).

Case 2: The need for empowerment and change of roles

How can women newly diagnosed with osteoporosis without preceding fractures be supported in self-management of the disease? By identifying their needs, designing and developing a solution, exploring how they experience it, and evaluating whether

⁷ <http://dx.doi.org/10.1080/17482631.2017.1307061>

mHealth (mobile health) can engage the women in treatment decision making and ensure a sense of self-management after being diagnosed. Our findings show that in general the women felt as if they had been left “in limbo” when diagnosed with osteoporosis. In general, the women requested targeted and tailored information about the disease, and said that they were willing to manage the disease themselves. However, they asked for more information in advance to prepare for their consultations and to consider treatment options, so that they could ask qualified questions and participate in treatment decisions. A 62-year-old woman expressed it this way:

It would have been nice if I could have some knowledge before I went to see the GP. If I would have had the opportunity to be more prepared about having osteoporosis and treatment options, then we could have had a dialogue.

To close the gap between the needs of the women and what the system had to offer, we designed an “app” solution “My Osteoporosis” which gave the women targeted information about osteoporosis and focused on the advantage of being diagnosed before a fracture has occurred. Through the app, women are able to receive important information before seeing their GP’s and also obtain information regarding different treatment options. We anticipate that women will then be better prepared and able to participate in treatment decisions, putting them on a far more equal basis.

Our pilot testing revealed an interesting finding: the change of mind-set gave the power (through knowledge) to the women, and as a consequence, disempowered the GP’s since the GP’s were now the ones who were not prepared for the consultations. One of the GP participating in the study stated:

As a doctor I must have the opportunity to be prepared for seeing the patient and find out beforehand how I can help the patient the right way in the treatment decision-making process. If the patient arrives at my consultation better prepared than I, I will become very irritated. This kind of surprise we have to avoid. We have to make sure that both parts are prepared for the consultation to achieve a good dialogue. (Jakobsen et al., 2017)

Case 3: How to create changes involving the users

Preterm infants are reliant on hospital admission for optimal treatment and care in order to achieve an ideal outcome. In the hospital in our study, infants are closely monitored in the neonatal unit by hospital staff in close cooperation with the parents. The hospital admission disrupts family routines and separates families, leaving the parents longing for home. To optimise the family conditions, we gathered parents and health staff for interviews and several workshops to identify their needs so that the parents were better able to manage nutrition, tube feeding and breastfeeding at home. The interviews and workshops resulted in the development of a telemedicine device – Neonatal Tele Homecare (NTH). This device provides close contact between the neonatal unit and family homes, including the options of videoconferences, chat messages and infant growth monitoring. When infants receive NTH parents experience

a growing feeling of empowerment in caring for their infants and being at home allows them to be together as a family “around the clock”. Offering NTH has had a great impact on the organisation in the neonatal unit as well, with the hospital staff feeling safe leaving the responsibility of infant care to the parents (Holm et al., 2016, 2017).

During NTH there is room for dialogue and the hospital staff see more empowered parents. Further, care for the families at home through the telemedicine device leaves the families with feelings of being united as a family:

It's not until the last two weeks that ... We haven't done anything but sit, look at each other and talk. Because ... Here at home ... there was room for us to talk about what the hell had happened the last 4 months in the hospital [father of preterm infant]. (Holm et al., 2016, 2017)

Discussion: Analysing the Ecology of Care

With the “Talking Stick” as a starting point for the discussion, we now investigate how the EoC issues are expressed in the cases presented.

The Talking Stick is an ancient Aboriginal tool used for centuries to help heal relationships through learning to listen to others and to speak your truth. It is used as a way to help connect people to one another and to begin a healthy dialogue through active listening.⁸

Being a human: The necessity of relationships

In Case 1, we meet patients who feel they are reduced to a hip, a problem, and not seen and treated as a human being in need of care.

You know people with a hip fracture are often old people ... even if you are old, they ought to see you as a human being. It is not our fault that we have become old and got some flaws. There should be room for us as individuals anyway... (Woman, aged 74 years)

The same woman also asked for just a little loving care as she stated that it is a basic need of a human being.

In Case 2, the women cry out for a more equal dialogue when meeting their GP's. The system is divided into sectors and the women feel like they are “being left in a jungle” without anything to do because they do not know how to prevent future fractures.

In Case 3, we discover families that no longer feel like families when admitted to the hospital: “It wasn't until we came home I felt that I had become a mother” [parent]. Being at the hospital, the culture and habits of the staff reduces people to being patients and forgets “the thousand little things...” [patient].

⁸ <http://www.inclusion.com/ttalkingstick.html>

Healthy dialogue through active listening

In 1927 a Boston doctor wrote in the *Journal of the American Medical Association (JAMA)* this holistic approach to his patients:

...all your patients whose symptoms are of functional origin, the whole problem of diagnosis and treatment depends on your insight into the patient's character and personal life, and in every case of organic disease there are complex interactions between the pathologic processes and the intellectual processes which you must appreciate and consider if you would be a wise clinician. (Peabody, 1927)

Dr Peabody not only extended a holistic approach to his patients but he also saw the beauty and maybe necessity of gaining satisfaction in practising care for patients:

The good physician knows his patients through and through, and his knowledge is bought dearly. Time, sympathy and understanding must be lavishly dispensed, but the reward is to be found in that personal bond which forms the greatest satisfaction of the practice of medicine. One of the essential qualities of the clinician is interest in humanity, for the secret of the care of the patient is in caring for the patient. (Peabody, 1927)

When looking at the pressure the system puts on the staff in Case 1, it becomes clear that knowing the thousand little things about your patient has no foundation in a modern course of treatment for elderly people with a hip fracture: “We have to think about discharge on the same day the patients are admitted otherwise we cannot maintain the flow which is needed” [nurse]. The system becomes more important than caring for your patients.

In Case 2 it became clear that there is a gap between clinicians and their patients – maybe due to lack of healthy dialogue and active listening.

In Case 3 we found how a change of mindset in parents with a neonatal child can change the EoC for the family. As Heidegger described (Bishop & Scudder, 1991), the negative side of care occurs when we (the professionals) take over care.

And the thing about coming home ... out there [in the hospital] ... you know, we don't know anything about preterm infants so we put all our trust in the nurses. But being at home, you get to make decisions on your own, you experience a bit more courage to say okay, let's do that. That you don't do in the hospital because you're left with the feeling that the nurses know best. (mother of preterm infant)

The question is: Why do the parents experience this? Talking to the parents and investigating their needs and wishes, we revealed that the families were at the hospital because the system had decided so and not because of the need for hospitalisation. The consequences of changing the organisation and the mindset not only more empowered families but also more empowered nurses who consequently developed proficiency and

increased work satisfaction. In conclusion, the new way of offering healthcare services is a path to a Health 3.0 approach.

Speak the truth: Change of mindset

In 2016 Danish politicians asked healthcare professionals if they would speak up if they experienced something critical in their clinical practice. Thirty-three per cent (33%) had experienced conditions of critical standards and 29% answered that they would be silent about it. 33% would not speak up for fear of being sacked.⁹ So what does it take to make the necessary shift in paradigm? First, we need to create space for a healthy dialogue, so both staff and patients/relatives dare to speak up when needed. In addition, how do we change the mindset to foster a new paradigm? In our studies we discovered a gap between the staff and patients, but what has been clear is the gap between the staff and the management. How can a healthcare system survive severe distance between those who should be the creators of a healthy healthcare system? We need to shift focus from valuing documentation over care. Hence, the question is: If we, as health professionals, can survive without care in the relationship with our patients – what will be left? Will hospitals be reduced to factories? Instead, leadership must be more inspirational than controlling and more about coaching than managing. Leadership must be courageous in letting care take the place of evidence – since evidence does not care.

The question, then, is where to begin? Indeed, it might not be the patient or the staff that needs empowerment but the management to begin with.

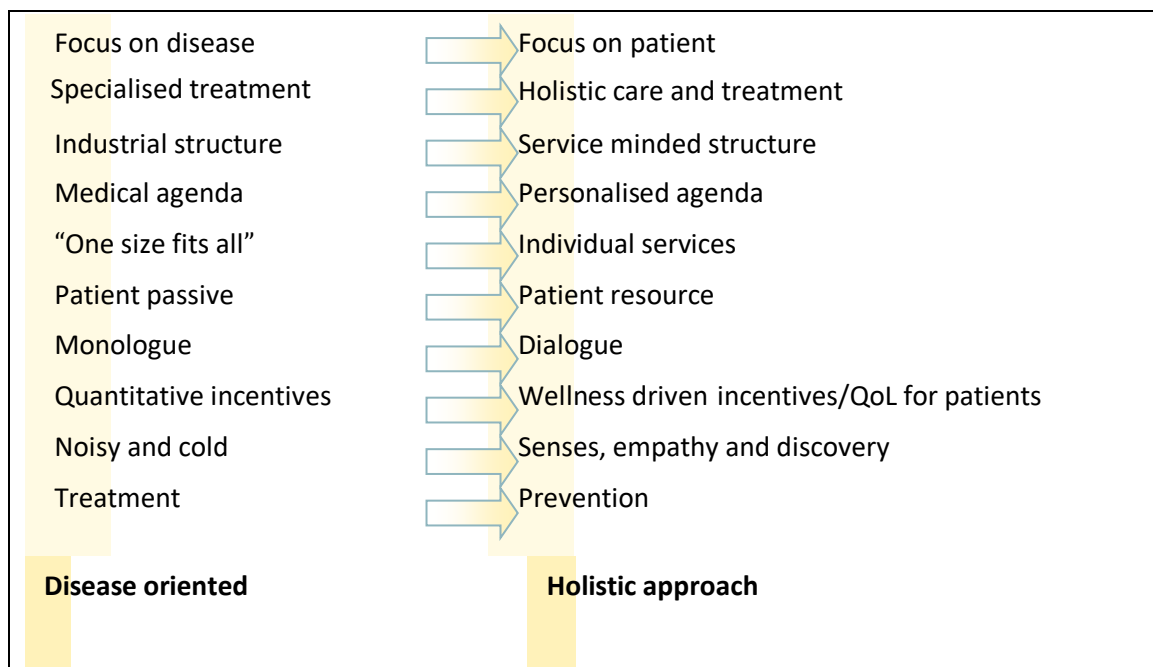


Figure 2. Change of mindset: The need for a new paradigm.

⁹ <https://dsr.dk/sygeplejersken/arkiv/sy-nr-2016-12>

Linking EoC to the healthcare context and to participatory design research methods, where the core values are participation and involvement of all stakeholders, could be an answer. Mutual learning and technology can be tools for change and EoC might be used as a complementary philosophy to help change the mindset of the stakeholders involved and thereby secure a holistic approach to one another (see Figure 2).

Perspectives

All of these conditions combine in the dawning of Health 3.0 and showcasing the value of using a patient's own resources as a way of facing the challenges described above. A person meeting these needs in this way can be described as Patient 3.0, namely, an empowered patient who is recreating the healthcare system in a more empowering way once he or she becomes a part of it. In this case empowerment may be referred to as enabling individuals to take control of their own health, wellbeing and disease management, and participating in decisions affecting their health and care (Faber, 2015). Furthermore, patients try to help each other to translate biomedical information into practical and useful knowledge (Dhillion, Lutteroth, & Wiinche, 2011; Pols, 2013; van Uden-Kraan et al., 2009).

In parallel to these developments, patients' usage of the internet and broader social media as an information-seeking platform, seems to serve two distinctly different purposes: The first is to get facts about their disease which will assuage their need for information. The second is to create communities where people are able to share experiences about their everyday life with an illness or disease, in order to be more active and empowered participants in the process of their own wellbeing. The *caules* from the tale ("moral of the story") about the Talking Stick tells us of the need for moving from the historic fixation on "the individual" and "the disease", to instead shift the focus to the holistic and complicated ecosystem each of us is a part of. Until then the care of the human will not be at the centre for our attention.

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About the authors

Jane Clemensen is a professor and head of clinical research at the Centre for Innovative Medical Technologies (CIMT) at Odense University Hospital with more than 13 years' experience with telemedicine research and participatory design. She is currently associated with six PhD students of whom she is the main supervisor for five. Jane's research projects all have their starting point in clinical practice, and involvement of all stakeholders including patients and relatives. They all revolve around the participatory design (PD) approach to research. Projects that use PD start by identifying and analysing the clinical problem or challenge and from that develop a solution or technology. This is in contrast to many projects that start by identifying a technology and then seek to find a clinical environment to test it in. PD is a well-known research design, especially within computer science, and it has also proven to be appropriate within health technology. Jane applied this design for the first time in a health science context in 2003 in her own PhD project, and she is a pioneer both in the fields of health technology and participatory design in health sciences. The co-authors of the paper belong to her research group and all have a clinical background.