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Troubling Care – A critical look at the systemic shift toward healthcare digitization

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Amid recognition that care is contentious and highly political, conscientious design in healthcare systems cannot simply work blindly toward what is thought to be 'good care'. Systemic design must grapple with the inherent conflicting values in care. This paper works to 'unsettle' care by exploring the tensions amid the evolving landscape of the Norwegian healthcare system. We attempt to embody Haraway's idea of "staying with the trouble" in a design process positioned within a systemic transition toward digitization in healthcare. Drawing on 14 months of fieldwork, we explore the contradictions and plurality of lived experiences in this context through textual and visual collages that intentionally juxtapose divergent values of care. This paper exposes an entanglement of troubles which include: knowing by measuring/experiencing through sensing; the situated view/the isolated view of the patient; and helping the dependent/coaching the independent. This research highlights that one important way of caring in systemic design might be to hold on to the troubles in the thick present, rather than reconciling or re-framing to solve emerging either/or tensions.

Keywords: Care; Trouble; Tensions; Digitization; Healthcare

Introduction and theoretical background

As design enters into the complex space of care, the 'politically-neutral' practice of creative product and service development is confronted by questions of human valuing that differ between people (Jones, 2013). *Care* has many meanings with inherent tensions between them: for some, care is self-less charity, while for others, it is reciprocity; care can be seen as paid labor, or thought to be incompatible with this; care can be about a warmth of connection, or a matter of discipline (Mol, 2008). Care is something "people shape, invent and adapt, time and again, in everyday practices" (ibid, p. 4). While care is omnipresent and a universal human need, it is also highly contentious (Puig de la Bellacasa, 2017). As such, scholars are calling for a politics of 'unsettling' care to stir up what is all too often sedimented when we think about working toward 'good care' (Murphy, 2015).

We see the need for design to move away from an emphasis on technofixes under the banner of working toward "good care" and instead create room for making trouble in care. Drawing on Haraway, we use the term *trouble* to denote entangled contradictions, multiplicities of meanings and a plurality of ways of being in the world. The aim of this paper, therefore, is to share a half-baked exploration of how design might start to unsettle care by exploring the patterns of tensions in emerging worlds within the evolving landscape of the Norwegian healthcare system. Drawing on situated knowledges from engagements in a long-term design research project in the Norwegian healthcare system, we muddle messy stories of thick presents that reveal "unfinished configurations of places, times, matters, meanings" (Haraway, 2016, p. 1).

Within Norway there is a great deal of excitement about and investment in digital solutions that will help more patients and reduce costs (Melby et al, 2019). Hospitals and municipalities are increasingly adopting new decentralized models of care to serve patients in their homes aided by digital technologies. These new models of care include emerging practices, such as medical distance follow-up, where patients connect through video conferencing for follow-up appointments (Aune & Aanestad, 2017) and home hospitals, where in-patients receive hospital treatment in their own home (Andersgaard, 2020). In this particular study, we zoom in on the troubles amid experiences of using remote care plans, where healthcare providers offer in-home support, guidance and monitoring to patients in their homes. What unfolds in this situated exploration is not an easy answer of a preferred future, but rather lingering and intertwined questions about differing values of care amid systemic shifts.

Messy-dology

The context of this research is set within the Center for Connected Care (C3), a long-term research and innovation initiative supporting a systemic shift within healthcare systems in Norway from centralized care in hospitals to distributed care in homes and communities. This research focuses on the use of remote care plans and the larger shift toward digitization of healthcare, explored in collaboration with system stakeholders. The stakeholders involved in the design research include two hospitals, a municipality, three health technology companies, two research universities, two classes of master students at The Oslo School of Architecture and Design (AHO) as well as patients and family members.

Our approach departs from a motivation to explore how design can work toward troubling care by delving into thick presents to better understand the tensions that exist within care systems. There is potential in bridging a systemic lens with theories proposed by Haraway as it holds value for systemic design. Approaches like GIGAMAPPING (Sevaldson, 2011) and Rich Design Research Space (Sevaldson, 2008) work with complexity and open up the mess of different realities, but they can be further strengthened by helping guide designers to stay with the trouble. Often in the analysis phase designers and design researchers have a tendency to move towards synthesis or a convergence of oppositions. The proposed approach leaves room for ongoing interpretation by immersing oneself in tensions and attempts to keep friction between different values of care. Taking a systemic lens and simultaneously staying in the thick present adds value when designing with the conflicting values in care. This research study was guided by the following research question: how can we understand care systems in a way that holds the contradictions and portrays the plurality of lived experiences amid systemic transitions?

In this study, we created visual and textual collages (see figures 2, 3 and 4) drawing upon our collective experiences over the course of 14 months. The foundation for our study includes 40 in-depth, semi-structured interviews, 44 informal conversations and 13 workshops. The majority of the workshops were held digitally, with a few exceptions held in-person. These workshops were generally attended by the same 12-16 people from our project partners. The interviews focused on different themes within the systemic transition like remote care plans, role of informal caregivers and cultural sensitivity in healthcare services. Being an active participant in the design process by conducting interviews, workshops and conversations gave us an embodied understanding of the context. After this, we identified non-exhaustive interview samples to move towards a smaller constellation of interviews. We re-read the selected transcripts from the interviews with patients and healthcare staff which focused on digital care services, and highlighted quotes that in themselves held a tension, or conflicting ways of viewing care or being cared for. Our intention was to seek contradictions across different stakeholders involved within similar care services. We then placed it on a Miro board (see figure 1) where we simultaneously worked with the quotes and images we found representative of the tension. From this we would write a summary and continue looking for quotes in the transcripts which helped to understand and expand on a particular finding. We then decided to use the format of collages. By combining text and visuals the collage opens up a reader to move into an interpretive way of reading an analysis. When one sees multiple things in juxtaposition, different things arise for different people based on their context and situatedness. The collage turns into a curated mess to wade in.
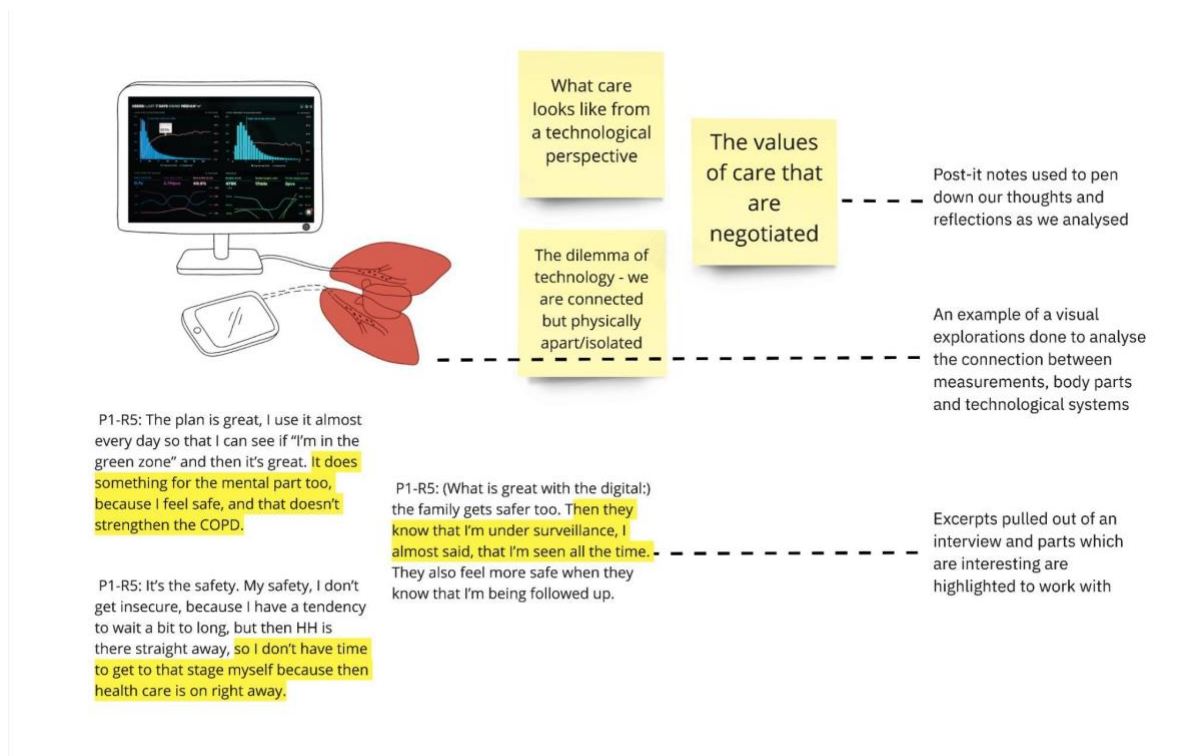
Figure 1. Screenshot of the Miro board showing how the interviews were used as material during the analysis (image of screen has been adapted from photograph by Luke Chesser).

This study explored textual and visual collages as a means to hold the contradictions and different realities that co-exist when working with systems transformation. The collages are attempts to stay in the 'thick presents' and capture the pluralities and conflicts of lived experiences. The process was structured into making three collages, two visual (see figure 2 and 3) and one textual (see figure 4), that were based on our gathered experiences from the interviews and workshops, drawing out and working with quotes from the material. In the textual collage (figure 4), we combined quotes from the interviews and workshops. Using theory as provocation helped us see the tensions between the multiple realities. The textual collage is typeset in three different fonts using different colours to indicate the three different realities of care (a nurse, patient and nurse-designer) being brought in contrast to each other. In figure 2 & 3, the quotes are combined with copyright free images found on the internet that were picked apart and pieced together to form new constellations. This became a way of thinking through making. The visual collages use juxtaposition and draw explicitly on the spaces in between the different realities portrayed, as a way to open up the experience of the tension for others. For example, in figure 2 we worked with images of medical measuring devices, hands which indicate touch, background of a table which could belong to a home as elements. These images were composed together with quotes from a patient, nurse and designer about the implications of using the remote care service. In figure 3, we worked with images indicating measurements, a representation of a person's lungs, interconnections between devices and body parts, and two backgrounds, one from someone's home and the other from a remote care response center. The images were combined together with quotes from a patient and a nurse. The collages try to go against the sleek and descriptive aesthetics often used to portray systems by combining the gathered data with abstract representations. In this way, they do not aim to portray an objective reality. As Haraway puts it; "It matters what matters we use to think other matters with". The resulting collages are an attempt to hold the contradictions and tensions, stay with the trouble and create materials to think within the thick presents (Haraway, 2016).
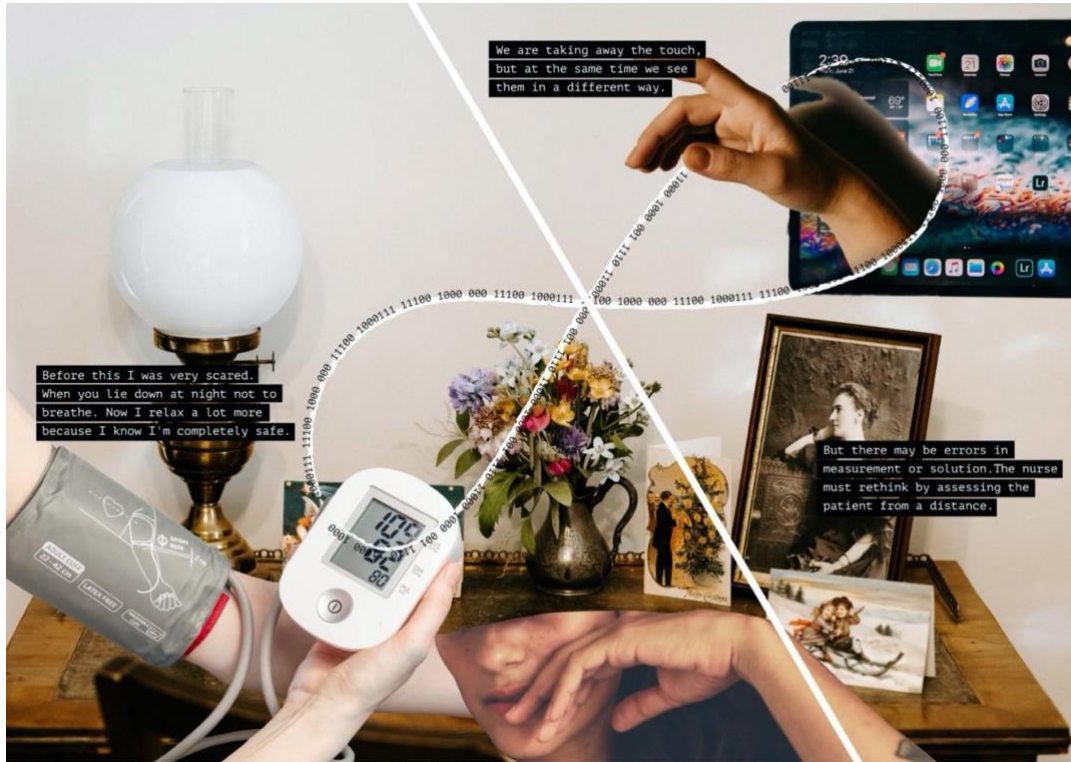
Figure 2. Visual collage by Shivani Prakash (adapted from photographs by Annie Spratt, Jonathan Borba, Mockup Graphics, Naomi August, Roberto Nickson)

Figure 3. Visual collage by Felicia Nilsson (adapted from photographs by Robina Weermeijer, Beth Macdonald, Luke Chesser, Linus Mimietz, Chris Ried, Adam Birkett, Anand Thakur, Helsehjelpen, Mockup graphics)

Patients need to take responsibility for their own health. The remote care plans are designed in a way to shift some of the responsibility of care onto the patient.

Some patients begin to see the value of remote care in a few months. Overtime, my team is able to create a sense of safety for the patient and their family. They need to see that we will be there for them when a measurement goes wrong. The patient needs to know themselves and their chronic disease. My team also gains an understanding of the patient through the monitoring. We begin to understand if such-and-such symptoms are normal or far from normal. I see some of my patients have become very well acquainted with themselves and have gained more responsibility for their disease. We are taking away the touch, but at the same time we see our patients in a different way. I think that they feel the same way, that we are listening more to them than we would have if we were home care and visited them every day.

But some patients are not really pleased that we don't work during the weekend. They feel unsafe that we are not sitting in the control room and monitoring them. Patients feel that they won't get a phone call if something went wrong. But that's the part of responsibility and knowing yourself. But, keep in mind, that every patient is not able to take responsibility for their chronic disease through these remote care plans. Some patients lose interest in monitoring and tracking their symptoms. In such cases, we are not able to extend any support. I need to spend my time on the patients who are interested in using the technology. You see, motivation is a key factor.

The nurses wanted to sign me up for a remote care plan. They are still testing the technology. It's all wireless, so it seemed less messy when I said yes to using their remote care plan. All I needed to do was measure two aspects daily. The measuring included recording my oxygen levels and blood pressure once in the morning. I reflected back on my daily routine. There can be space for two measurements.

After a few weeks, it felt great. A nurse called me every time a measurement shifted and checked-in on me. They weren't there during the weekends. But I'm healthy enough to be left alone. If I'm having a bad day, I know I can have two bad days before I need to get nervous. The plan is great, I use it almost every day to see if "I'm in the green zone" and it does something for the mental part. I feel safe, and that doesn't strengthen the COPD.

And then it's about how I feel. I wrote to them when I felt dizzy, and bang they were at home with a blood pressure monitor for me. Then they contacted the general practitioner and got me an appointment. I think it is very reassuring because I feel in control. If something happens to my body that I have no control over, I become very insecure. But now I can go into the plan and see my symptoms and which measurements I can take. I'm very fond of the remote care plan and I use it a lot.

There may be errors in measurement or solution. But the nurse can take a video call and check-in with the patient. If the patient looks fine then there may be a fault in the equipment. The nurse must rethink by assessing the patient from a distance. My experience is that they fix it well, but have to think and work differently.

But we need to proceed cautiously as somethings may go wrong sometimes. A patient may not really be in the yellow zone, and they may have consequences if they then do 'yellow' activities. There are human failures on equipment or assessments made by the health personnel. For now we chose to move away from automation for that security. But when things start to get more secure with the current system, then we can start thinking about it again.

Figure 4. Textual collage by Shivani Prakash including quotes from a patient, healthcare staff and developer

An entanglement of troubles in care

We examine the specific implications of the digitization of the remote care service and the effects of this transition on the connected systems. Through this approach, tensions, negotiations and troubles begin to become visible as we examine a shift from physical care planning to a remote model of care delivery. We see an entanglement of three troubles emerging from the making of the collages and they are unpacked below:

1. Knowing by measuring / experiencing through sensing

"We begin to understand if such-and-such symptoms are normal or far from normal", shares a nurse. The healthcare professional continues to build an understanding of a patient based on their individual symptoms gathered by measuring overtime. The understanding of one's body is designed into being dependent on a set of measurements which indicate a 'normalcy' of the body where the patient works toward staying in a particular zone. There are three zones in the plan - green, yellow and red - each indicating the severity of the patient's symptoms. Meyer (2003) argues that in care settings a knower can often become alienated from their body and their senses due to colonial healthcare practices. For example a patient described, "Sometimes I can feel that I have pain and then I check the measurement and it says it is fine and then I can calm down."

What are the consequences of creating a dependency on understanding the body through these 'zones' and remote measuring devices? Willis (2006, p.70) describes how "we are designed by our designing and by that which we have designed". In this context, the remote care plan begins to design the patient's knowledge of their chronic illness based on a zone. *Knowing by measuring* guides the patient to have a 'green' day if they are in the green zone and do green activities. For example a patient described, "the plan is great, I use it almost every day to see if I'm in the green zone". But we need to be aware of technological and human errors in measurements as a designer-nurse working on the service pointed out, "A patient may not really be in the yellow zone, and they may have consequences if they then do 'yellow' activities."

2. The situated view / the isolated view of the patient

Today the basic version of the digital remote care plan is designed to be used by the patient, a nurse and a general practitioner with the possibility of adding family members. A nurse will begin by setting-up a remote care plan for a patient through a physical meeting. Once the plan is set-up, the patient can live more independently and not be tied to the physical location of the healthcare service. Once the patient is at their home, the plan creates an isolated, individualist view of the patient's social setting for the healthcare professional. "My team also gains an understanding of the patient through the monitoring", said a nurse. The healthcare professional cares through controlled contact. A nurse will only reach out to a patient if a certain measurement is below the line of 'normalcy'. Based on their assessment, they may make a home visit which allows the nurse to have a situated view of the patient. A patient shared their experience, "It is very reassuring. Measured and 2 minutes after Helsehjelpen was on the phone with me. My saturation was low".

This sense of safety is created overtime based on the experience of follow-up calls and visits. If a patient does not hear from a nurse, then the patient should assume that they are doing fine. But how should a patient know that they are doing okay? A nurse shared, "some are not really pleased that we don't work during the weekend because they feel unsafe that we are not controlling. They don't get a phone call if they get something wrong. But that's the part of responsibility." On another note, several family members benefit from knowing that their loved ones are doing okay and that a healthcare service 'has the patient's back'. This might lead to the family members not needing to frequently connect with the patient directly. As a patient shared, "'Then they know that I'm under surveillance', I almost said. That I'm seen all the time".

3. Helping the dependent / coaching the independent

A nurse shared, "So, by using this [remote care] plan, that also raises the responsibility and awareness for the patient." It does so by transferring some of the responsibility of care onto the patient. The distribution of the labour of care is an ongoing negotiation between the patient and the healthcare provider. But this division of labour is troubled when a patient is not able to help the nurse by taking their measurements and reporting their symptoms. Another nurse shared an example, "I'm like, why didn't you tell us that you had a sore throat? You know that's a symptom. But he doesn't see it that way. He is a man, and he's stubborn, and it will go over, it's just a sore throat." If a patient doesn't report any measurements, the nurse will immediately call them to check on

them. The patient needs to quickly adapt and become an expert in creating a symptom-based understanding of their chronic illness. But if they fail to do so, it could result in multiple trips to a hospital, which is what the remote care service is designed to avoid.

For some patients there is validation in the measurements that helps reduce their burden of self-care. "If I have a bad day, I know I can have two bad days before I need to get nervous. Then the [municipal remote care service] staff are on it straight away." In this context, there is a tension in the role of healthcare professionals between being a coach and being a helper. On one hand, as described by a nurse, they might "handle patients with 'their hands behind their back', wanting them to do as much as possible on their own, while other nurses would say 'let me help you'." The staff continued by sharing some of the resistance to this shift: "some workers are sceptical because of the fear of losing warm hands, and distrust in technology in general." Questions arise around dependence and independence. What happens when some patients want or need direct help? Who holds the burden? If healthcare providers do not take on that burden, who is it passed on to? The views on these shifting roles and responsibility held by designers and developers also influence how remote care plans are shaped. One technologist shared, "in the end the only person that can affect their own life is the patient themselves, it's difficult for us to force the patient into doing something."

Discussion

In our design research, we attempted to share an entanglement of troubles emerging from a systemic transition within the Norwegian healthcare system. It is a shift which is embraced and accepted as a utopic future. We have begun to trouble this context of digital healthcare which is generally seen as unproblematic. By using theory to understand ongoing changes, juxtaposing images and quotes from interviews, we noticed that this analytical process enabled us to be more reflective about the context we are working in. Based on our learning from troubling this hard-to-critique space, we would like to share the following points for discussion and reflection in systemic design.

1. Wading in tensions

While arriving at the entanglement of troubles, we saw ourselves oscillating between different facets of tensions. We were immersed in the present to the extent that we saw tensions dissolve, but then again, we saw contradictions emerging. For example, the remote care plans are enabling patients to live more independently by distributing the labour of care. But then with what value of care are they doing so? Sustaining a tension in one direction could have major risks for society. Attempting to stay in the thick present, we wade in tensions amid conflicting realities rather than neutralising multiple realities by arriving at a reconciliation between the tensions. Through unpacking the ongoing unsettling by technology, we realise that there is no objective reality in this transition and that we are only able to capture some realities. Our understanding of the multiplicities of care is limited by our own situatedness.

2. Messy learning processes

During a follow-up workshop conducted together with the partners, one of the healthcare providers reflected on the importance of considering the potential negative aspects of remote care, even though the participant's work is focused on implementing and developing this service. The process helps participants to understand perspectives at tension within their own work. We see this tension-based understanding offering our partners approaches to move away from a one-sided perspective of this systemic transition and begin embracing the multiple realities that exist with their care contexts. Staying with the trouble has implications for the narrative of the story. Rather than ending with a shiny conclusion, we see this exploration as a messy ongoing learning process. Through our explorations, we attempt at offering the stakeholders a platform to engage with tensions, thick presents and troubles about their work contexts and thereby, embed the learnings within ongoing design processes in organisations.

3. Caring by keeping the friction

This work raises questions for us about how shifts in systems are 'teeter-tottering' between different values in care. The care that is scalable often gets amplified in our society. This need to care efficiently is entangled with caring for fragile, unpredictable bodies which need varying amounts of care. If care holds values contradictions,

then designing in care needs recognition of these different tensions. By staying with the trouble, we question what value of care designers are enacting or should enact within this systemic transition. By attempting to bring in a critical view of how technology is designing us back, we raise questions about the lived experiences and realities that are being amplified through this systemic shift. Amid these entanglements, we suggest that one key way for systemic designers to show care could be by keeping the friction, which means not reconciling the either/or in the tensions between different values of care but rather holding onto them throughout the design process. Inspired by Haraway, we suggest that 'it matters with what care we care for our systems of care'.

Acknowledgements

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