

# The Virtual Clinical Encounter: Emplacing Patient 2.0 in Emerging Care Infrastructures

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Telemedical devices such as the Patient Suitcase for treating chronic heart failure patients at home have been suggested to foster new and empowered patients. In this paper we analyse to what extent the 'virtual clinical encounters' taking place through the Patient Suitcase can be said to have such effects. We find that new skills are developed for all actors involved and that the work involved in the consultation is largely shared, but the normative claims of an independent and self-managing 'Patient 2.0' are difficult to support. Rather than seeing this as a dismissal of the transformative effects of telemedicine, we will suggest the need to decentre the attention from the individual and include the place-making efforts and effects involved in emplacing telemedicine in the home. The technology does not move work, knowledge and power from one actor in the clinical encounter to another – rather it redistributes and transforms it among more actors and more places demanding continuous sharing of work, development of new skills and involvement of distant and at times unruly actors. This may provide more sober accounts of the ways in which telemedicine has implications for the kinds of patients we may find in contemporary healthcare and awareness of the more ambiguous relations between self, place and other in emerging care infrastructures.

*Keywords:* telemedicine, patient 2.0, the virtual clinical encounter

## **Introduction: The Patient Suitcase**

Your suitcase is your own. It contains belongings that you need while travelling to maintain your looks, your routines, your identity. It allows you to go elsewhere; with a suitcase you don't have to either choose to stay at home or leave everything behind. The Patient Suitcase, however, is not for the travelling of people – quite the opposite. It is a telemedical device that allows the patient

with chronic heart failure to stay at home rather than having to visit the hospital for regular check-ups. What travels is not the person using the suitcase – rather it is the foreign places of the healthcare system, which travel into the home of the patient through the suitcase. And it is the data generated about the body, which travels from the home to the clinic. Through the web-cam and screen of the suitcase the patient and a health care professional

can meet for virtual consultation. This arrangement, as many other telemedical devices developed and implemented in recent years, is to support, at a distance, the treatment of the patient with a chronic illness. Where the conventional suitcase is supposed to help the owner to stay unchanged, the patient suitcase is supposed to change the patient into a particular kind of patient: a knowledgeable, self-caring, self-managing patient. A patient 2.0.

In the call for this special issue this hope for technologies' transformative power for the kinds of patients we might meet in the healthcare system is framed with this reference to 'Patient 2.0'. This figure may, as the call also suggests, first and foremost be seen as an imaginary endowed with various normative expectations as to the effect of Information and Communication Technologies (ICT) for the increased, legitimate and productive participation of patients in treatment and knowledge production in healthcare. As in the case of the 'Web 2.0' concept there is a strong focus on the user-involving aspects of ICT and its effect on the redistribution of power and agency among those participating in a particular arena. Patients in actual medical practices introducing telemedicine may not be directly confronted with the normative visions for a technology-induced transformation of their role as patients. But the technologies, which they are asked to use at home, are indeed inscribed with some of these visions (Akrich, 1992).

In this paper we want to explore how elderly patients engage with telemedicine at home and discuss how they may be said to become particular kinds of patients. Analysing data from an interview-study on the use of the Patient Suitcase among people with chronic heart failure, we want to discuss how issues of space, role and agency must be rethought with the emergence of new kinds of spaces for clinical encounters,

such as the virtual encounter. How do such encounters taking place in the home fit the normative visions related to telemedicine and by extension to the notion of 'Patient 2.0'? Drawing on recent work on tele(health)care in Science and Technology Studies (Mort, Finch & May, 2009; Roberts, Mort & Milligan, 2012; Oudshoorn, 2008; Oudshoorn, 2012; Pols & Moser, 2009; Langstrup & Winthereik, 2010), Computer Supported Cooperative Work (Christensen & Grönvall, 2011; Aarhus & Ballegaard, 2010; Fitzpatrick & Ellingsen, 2012) and Human Geography (de Certeau, 1984; Tuan, 1999) we will argue, that this body of research challenges the notion of 'Patient 2.0' in two ways: first, when these telemedical arrangements are studied as socio-technical infrastructures (Star, 1999) that redistribute agency among human and non-human elements, the agency of the patients seem highly contingent on the arrangement in question and their durability. It is thus difficult to argue that patient *per se* become more independent from using telemedicine. Rather, patients and professionals share work. How they do this is specific to the technologies (Willems, 1995; 2000; Mol, 2000) and sites (López & Sánchez-Criado, 2009; Schillmeyer & Domenech, 2010). Second, directing our attention towards the way in which the Patient Suitcase is *emplaced* within the home as a meaningful place (Tuan, 1999) it becomes clear, that focusing on *the* Patient 2.0 – here the patient with heart failure – may make us overlook the central transformations implied with telemedicine – namely those that have to do with the emergence of new and potentially contentious spaces of care. Decentring the clinical encounter implied with telemedicine and similar technologies also demands a decentring of the notion of Patient 2.0: Rather than being an individual characterized by increased autonomy and knowledge it might be better understood

as a particular ambiguous relation between self, place and other.

### **Telemedicine and the Clinical Encounter: Patient 2.0 in Place**

Telemedicine and telecare are increasingly becoming central nodes in the health care structures being weaved in Denmark and other Western welfare states. The visions in Denmark are clear: Policy makers portray telemedicine as having the potential to simultaneously improve quality of treatment of primarily chronic diseases and lowering costs, because patients can be discharged from the hospital earlier – or not admitted at all (Danish Regions, 2010). Patient advocacies also believe telemedicine to be a way towards patient-centred care by involving patients and their individual needs to a greater extent (Danish Patients, 2010). Thus, by enrolling the home and the patients and framing both as yet unharnessed resources, in policy documents, telemedicine is portrayed as a revolutionary way of treating patients, which has the potential to replace other forms of treatment and communication in the healthcare system. Most notably, the clinical encounter where doctor and patient meet in the institutional setting of the clinic or hospital will be avoided, or it will be relocated by webcams or on-line communication to the privacy of the patient's home environment. Through such 'virtual clinical encounters' and equipped with online 'tools of care' (Willems, 1995) the traditional, passive patient will – or so it is expected – in consequence be substituted by a new and more empowered, knowledgeable and self-caring patient (Kendall, 2001; Bos et al., 2008).

But how is it that some have come to consider the specificities of the clinical encounter in medicine as something which has effects on what a patient might be? Here

we have to look at not just the practices of medicine, but more so the sociology of medicine and its direct impact on policies and practices. Sociological interest in the relations between the clinical encounter and individual notions of self were at the centre of Parsons seminal work on the patient role (Parsons, 1951). Parsons suggested the patient role to be a role with a central function in the overall social structure. The doctor was seen as a legitimate agent of this structure, authorized through his socially sanctioned role to relieve the patient of his or her responsibilities related to other functions in the structure (as a worker, a parent, a citizen) while they were inflicted with disease. The patient is given a different role – the sick role – through the dyadic interaction taking place in the privatized space of the clinical encounter. Carl May has suggested (2007; 2010) that the primacy of the clinical encounter as a privatized, proximal relation as found in the Parsonian account, still frames our understanding of the clinical encounter in the sociological literature broadly. Even within the comprehensive critique of the notion of 'the sick role' and the asymmetries of power it entails, which has been at the centre of medical sociology during the last 30 years, the clinical encounter has generally been addressed as an individuated relation between the health professional and the patient (May, 2007; 2010); one in which power and knowledge flow in a lineal manner, shaping the roles and identities of the actors involved – most often in an asymmetrical way (Lupton, 1994). The critique being raised towards Parsons and towards the practices of medicine found to disempower rather than relieve the patient, foreshadows current suggestions in relation to telemedicine that a more empowered patient may come out of the transformation of the clinical encounter through technology. Thus, among proponents as well as critics

of telemedicine there seems to be a shared focus on which changes telemedicine might bring to a patient's role – or agency – in the doctor-patient relationship. Do we empower the patient by allowing for a more symmetrical relationship (e.g. Ball & Lillis, 2001)? Or do we lose the uniquely dyadic, personalized relationship between patient and professional when using online consultations (Evans, 1993)? These questions of doctor-patient dynamics seem obvious to examine in their own right. But concurrently with the increasing distribution of the health care system which blurs the established distinction between on- and offline care, scholars have pointed to a need for refocusing our analytical gaze towards the chronic care infrastructures (Langstrup, 2013; see also Star, 1999) or corporate ecologies of care (May, 2010: 135) allowing for information, treatment, and bodies to be distributed and coordinated. Clinical encounters then, May (2007; 2010) argues, are to be understood as sites of work and not only in terms of a relationship between doctor and patient, but just as much in terms of *who* and *what* (else) is taking part in them and *where* these encounters take place. The notion of place is of importance here, not as a stable spatial container of social activity, but as the ongoing making of meaningful spaces (e.g. Tuan, 1999; de Certeau, 1984). The home (as well as the clinic, for that matter) may be seen as one such accomplishment of 'ongoing and mediated interaction between self, other and place' (Gorman-Murray & Downing, 2007: 5). Strategically including the home as a site of work raises questions as to the implications for place-making – or more specifically how actors manage the relations between self, other and place as virtual clinical encounters unfold in their home. We should in other words decentre our analysis of the transformations implied by telemedicine from the focus on the

change in patient role alone. The '2.0' next to the noun 'patient' in 'Patient 2.0' should always already imply this decentring as it more than hints at the infrastructures making new clinical encounters take place. However, at least in the vision related to telemedicine, all attention seems to rest on the patient in isolation and little attention is being given to the sociotechnical care infrastructure including specificities of technologies, spaces and other human actors. In recent studies from the overlapping fields of Computer Supported Cooperative Work (CSCW) and Science and Technology Studies (STS) some help is to be found: CSCW has a long tradition for analysing the cooperative work practices distributed spatially and temporally as a consequence of information technology (e.g. Schmidt & Bannon, 1992; Vikkelsø, 2005), and recently a number of studies have addressed the issues of telemedicine and IT-supported home care in terms of new collaborative practices involving a more diverse collective of actors thus posing new challenges to design and use (Christensen & Grönvall, 2011; Aarhus & Ballegaard, 2010; Fitzpatrick & Ellingsen, 2012). Within STS Roberts, Milligan and Mort (2012) have pointed out the increased involvement of telecare-workers, who monitor the data submitted by telecare technology and take calls from the citizens having these technologies installed in their homes (see also Oudshoorn, 2008). Lopéz and Sánchez-Criado (2009) have shown how telecare technology promotes a particular spatialization of care, in which the home is cast as a safe haven and autonomous space for elderly citizens. However, when analysing specific telecare arrangements in Catalonia, Spain, they find that the boundaries between public and private, between the autonomous and the collective are not given even in the context of the home and that such boundaries continuously are negotiated and redrawn in

relation to the introduction of telehomecare (Lopéz & Sánchez-Criado, 2009). These and other studies draw attention to the active role that technologies and spaces (see also Schillmeyer & Domenech, 2010) play in telemedical arrangements. Drawing on these insights, we are interested in looking at the establishment of virtual clinical encounters, their emplacement in patients' homes and in the relations found there as well as the implications for re-configuring actors and spaces in the larger ecology of care.

### Context and Methods

The research for this article was carried out in 2010 in connection with but independent of a larger clinical study on the use of a telemedical technology, the Patient Suitcase, for chronic heart-failure patients: The Tele-heart Failure project (Telehjertesvigtsprojektet, 2009). The clinical study consisted of two sub-studies: sub-study 1 focusing on treatment outcomes for newly diagnosed patients with chronic heart failure and sub-study 2 focusing on early discharge from hospital of known chronic heart failure patients (Telehjertesvigtsprojektet, 2009). The telemedical patients were in both instances compared to a group of chronic heart patients receiving conventional treatment. The qualitative study reported in this paper consists mainly of interviews with patients and health professionals involved in the Tele-heart Failure project. Patients were recruited from both sub-study groups by the health professionals responsible for the clinical study by asking whether the participants would be interested in giving an interview about their experiences of using the Patient Suitcase. Seven patients aged 49-83 were interviewed using semi-structured interview guides. The participants were or had been either skilled or unskilled workers and they all lived in

Funen, an island in the Southern part of Denmark. Interviews were conducted in the patients' homes and during some of the interviews the spouses also engaged in the conversation. Also the physician running the study and one nurse involved were interviewed, as was a technical advisor from the company responsible for developing the Patient Suitcase. All available written material on the Tele-heart Failure project and the Patient Suitcase was collected and one on-line consultation with a chronic heart patient was observed in the clinic. All interviews were digitally recorded and transcribed. Field notes were made after both observation and interviews. The transcribed and written material was coded and thematized and further analyzed using the tools and principles of situational analysis (Clarke, 2005). This involved identifying the human and non-human actors involved in the virtual clinical encounters and mapping their relations in and across what Clarke (2005) calls social worlds/arenas, but which we conceptualized as a broader ecology of care stressing the spatial dimension.

### Division of Work in the Virtual Clinical Encounter

The visions related to telemedicine are often stated to be ones of *giving* patients responsibility and thereby making them responsible for a much larger part of their own care – e.g. for monitoring their body. In the Tele-heart Failure project this vision is explicitly framed as patient education:

The idea was that the patients can improve their compliance if they receive information in their own home, on their 'home turf', and that they will become more knowledgeable if they participate and manage the measurements of weight, ECG and blood pressure themselves (Project manager, e-mail correspondence, 2010).

In this quote the project manager links the production of both compliance and insight to participation and the self-management of measurements. But looking at the very design of the patient suitcase one may reconsider if participation and self-management is the same thing. Here the patient seems to be inscribed (Akrich, 1992) as a participant in a distributed set of tasks, rather than as a manager. These inscriptions point back in time to the initial design of the Patient Suitcase involving among others a senior physician, wanting to free up beds in the hospital, an IT company wanting to expand their business to the area of eHealth, and various governmental and regional actors partly financing innovations that could lead to a reduction of costs for healthcare (Erhvervs- og Byggestyrelsen, 2009). This large crowd of actors are indeed to be seen as part of the corporate ecology of care, but in the following we will focus on the way in which the final design of the suitcase configures both the patient and the health professional in the on-line consultation.

The patient suitcase looks like a small, black suitcase or large briefcase. When opened it is revealed that a screen, two built-in loudspeakers, a small camera lens and some sockets occupy one of the two halves, while the other half is closed off by a plastic lid, hiding the electronics inside. The Patient Suitcase has an on/off button, and an alarm button. The suitcase is the hub through which the patient and the nurse or physician can see and hear each other and data are visualized and sent. The actual production of data is not accomplished by the suitcase alone, but rather through measuring devices connected to the suitcase: ECG-electrodes, measuring electric activity of the heart, blood pressure cuffs, scales, and a small switchboard making it possible for the user to switch between the different measuring devices connected to the suitcase. Only the patient

can thus do the shifting between the various measuring tools. Most of the devices are foreign to the average home-environment. Only the scales look like something most people have as part of their household though data from this household item rarely become distributed beyond the bathroom. The measuring devices are all known items in the clinical context; however, they are the tools of the clinician. The suitcase, the switchboard and an internet connection have allowed these tools to be relocated to the patient's home without being disconnected from the clinic. The measuring devices are meant to function only in relation to the suitcase and thus do not entail that the job of making measurements is given to the patient to use autonomously, but rather that the tasks involved in making measurements is distributed spatially and temporally among more actors (nurse/physician, computer screen, internet connections, suitcase, measuring devices, switch board and possibly more) in new ways.

Below we will look closer at how this may influence whether the patients become more knowledgeable and responsible. But first, let us explore in more detail how the patient is a participant in the task of measuring in an on-line consultation:

Although there is still 10 minutes to the appointment, Ben has turned the suitcase on. It is 'to warm it up', as he calls it. Before the appointment Ben makes an electrocardiography (ECG) on his own. He attaches a moistened electrode to his wrist and ankle and waits for the graph of the electrocardiogram to be recorded. During the consultation this recording can be transferred to the health professional. Before tuning in, Ben straps the BP-cuff to his arm. After a short dial-up tone the nurse, Maria, appears on the screen. First thing, after greeting each other, Ben asks Maria if



she would like a BP-measurement. She responds positively by saying that she will now measure it, and pushes a button at her desk, that causes the cuff to inflate around Ben's arm. After about 35 seconds they have a measurement. Both of them can see the numbers. It is a bit high, they agree while Ben takes off the cuff. Moving on to the weighing, Ben turns the switch and steps onto the scales [The switch has to point at the ongoing type of measurement (ECG, BP or weight) to ensure that data can be transferred to the hospital database, ed.]. The scales are unreliable, Ben comments, compared to his own scales in the bathroom. While weighing Ben, they joke about whether Ben or Maria is ahead of the other in the course of the consultation, and they small talk about the new car that Ben will be picking up tomorrow. Maria then asks him if he has turned the switch yet, so that she can obtain the data of the ECG. He hasn't, but he then does. Maria tells him that the ECG looks fine. They continue the consultation by discussing the course of his medication – when and how much to change the dosage, how and where to obtain more medicine. They end the conversation by making a new appointment for another on-line consultation. (Field notes, 2010)

In this field excerpt Ben comes forth as a very active patient. He starts measuring even before the nurse turns up on the screen. He handles the demands of the Patient Suitcase, to be warmed up, before the consultation. He has been given instructions to do this as he was enrolled as a participant in the research project when he was found to suffer from chronic heart failure at the hospital. As we see, the patient as participant in the task of monitoring inscribed in the design of the Patient Suitcase is also enacted in the on-

line consultation. The physical separation between him and the nurse implies that he must engage in practical activities, which in conventional treatment would be attended to by the health professional (e.g. attaching electrodes to his body, fastening the BP-cuff around his arm) or which are quite novel to these types of consultations altogether (turning on the Suitcase, turning switches). Some of these activities he manages without instruction – at this point in time – by the nurse, while others, such as turning the switch on the switchboard, he is reminded to do by the nurse. Also, while he himself applies the cuff for blood pressure measurement, it is the nurse or physician, who from her or his location within the hospital activates the mechanism that allows the cuff to inflate. The set-up does not allow the patients to make this measurement nor the ECG by themselves as it depends on the coordinated activities of patient, suitcase and nurse.

So while the suitcase is in the home of the patient the task of measuring both BP and ECG is distributed more widely over various locations and actors. This implies a lot of articulation work (Strauss et al., [1985] 1997) in the course of an online consultation. In contexts of cooperative and distributed work activities as these, articulation work may be seen as the often invisible work involved in coordinating and integrating these activities (Strauss et al., [1985] 1997) – work involving and shaped by both humans and technologies, as it has been well-documented within CSCW (Schmidt & Bannon, 1992; Star & Strauss, 1999). Due to the lack of physical proximity (Malone, 2003; Oudshoorn, 2009), instructions have to be given through voice and gestures during the consultation. For example, health professionals asked patients to examine their own legs for oedema, as the health professionals could not touch them. The patients needed to touch – or palpate, to

use the clinical wording – their own legs and try to describe their sensation to the health professional in words, hereby translating a visual and tactile feeling into an audible description perceptible to others and transportable across the network. As other scholars have noted (Oudshoorn, 2009; Pettinari & Jessopp, 2001; Roberts, Mort & Milligan, 2012), this means that adequate oral and visual communication skills become obligatory points of passage and important allies for a successful cooperation and treatment.

The online coordination, the articulation work and the oedema assessment are fine examples of how work associated with clinical encounters in telemedicine shape – and is shaped by – a distributed network that clearly extends further than the health professional’s office, but also that the work and responsibility is not simply given to patients. Care work is highly collaborative (Christensen & Grönvall, 2011) and in this case patients, professionals and technology perform ‘shared work’ (Winance, 2010) in which new dependencies and independencies emerge and thus also a need for new skills. The professionals increasingly depend on the ability to verbalize instructions for this kind of ‘patient work’ (Strauss et al., [1985] 1997) that is needed for the consultation to move forward. These skills of producing ‘virtual co-presence’ are largely ignored when discussing the prerequisites for good telemedicine or telecare (Roberts, Mort & Milligan, 2012: 498). The patient may be said to become able to do independent care-work, when he or she starts the ECG procedure by attaching the electrodes and makes the reading before the consultation. This is indeed a new skill alongside others that the chronic heart failure patients in this study can be said to have acquired. However, as we will see below, this may be a too operationally segmented account of

what counts as dependent or independent, not least if we want to connect this to overall notions of new forms of patienthood.

### ***Knowing the Numbers***

When interviewing patients, they were all able to describe in much detail the tasks they had to manage in relation to the consultation: warming up the suitcase, putting on electrodes, using the switches and more. However, often they could not remember the names for the different measurements, nor did they feel confident interpreting the numbers. A patient describes her engagement in the measurements in the following way:

C: ‘... I received very good instructions. I was able to measure myself, oh what is it called.... Ah... heartcar... oh, what is it called, it is called something in particular...’

Interviewer: ‘ECG?’

C: ‘Yes, that it. I had to put the thingies on my wrists and on one ankle. And then I could measure, so it, this ECG, was done when the nurse called me up.’  
(Interview with patient, 2010)

Actually, the question of independency and responsibility may be experienced as somewhat unclear, as these quotes indicate:

A: ‘I could measure... well, it wasn’t me (smiles) I just had to put it on and then... Tom [the physician, ed.] would start it, I couldn’t even turn the instrument off (...)’

Interviewer: ‘So you just told him the numbers, or, I guess he could see them, right?’

A: ‘Why yes, he did the blood pressure measurement himself, you see’ (Interview with patient, 2010)



The patients are given tasks related to measuring – turning on the Suitcase, putting on the electrodes and the cuffs, but they experience the measuring itself – inflating the cuffs, reading the measurement – as something which is done by the health professional. So even if the work may be seen as collective, the patients experience the primary tasks as being carried out by the professional.

F: ‘there weren’t that much to do... because there were, as I said, I had to be weighted and... then, when I had to have my blood pressure taken, right, then I just had to put on the cuff and then Maria [the nurse, ed.] would push the button down there [in the hospital, ed.]. She could do that. And then... then... I could see on the instrument that it... what it showed, you know. Yes, yes, that I could see, yes.’ (Interview with patient, 2010)

The patients see the measurements on a small display, which is turned on by the health professional and the number is often commented on by both participants as in the field excerpt in the beginning of this section: Ben engaged in commenting and reflecting upon the meaning of the numbers. The blood pressure was a bit high, they agreed, and Ben was annoyed that the scales are not as stable as the ones he uses in the bathroom. Ben is, through the online dialogue with the nurse, actively engaged in reading the numbers and interpreting what they might mean to his treatment. Other patients engaged with great enthusiasm in the tasks enabling the production of measurements, but in the interviews they were hesitant in engaging the interpretation of the numbers:

G: ‘Well, I don’t know anything about what those numbers mean, I don’t

(smiles), but you know, it [the blood pressure] cannot be too high when she [the nurse] doesn’t talk about it... it can’t be.’ (Interview with patient, 2010)

D: ‘Well, I weren’t told the numbers as such ... and I didn’t ask either... because he [the doctor] was the expert, you know. If he says they are fine, then I assume that’s how it is...’ (Interview with patient, 2010)

These patients perform all the tasks assigned to them – they put on electrodes, turn on the suitcase, put on the cuff – but they do not engage with the numbers. They do not experience this as a task assigned to them.

This is however in contrast to how the nurse envisions the patients’ engagement with the numbers as she expects them to become *owners of measurements*:

... Well, they simply have to get involved. They can’t just come in here [at the hospital, ed.], deliver a body on which we can do some measurements and then go on home. It is their measurements and they are the ones handling the medication. And now I am the one asking them for something too. (Interview with project nurse, 2010)

In this quote the nurse contrasts the traditional encounter in the hospital with the online consultation via the suitcase: In the former the patient ‘delivers a body’ and in the latter the patients produce their own measurements and it is the nurse, who has to ask for the data. In her account the powers have been, if not reversed, then at least balanced, because the patient has his or her own data. However, we have seen, this implied symmetry might not be as evident. The nurse does ask the patient to do certain things – put on the cuff, stand on the scales, flip the switch – and the results of the measurements are accessible

to both parties simultaneously. Though, what seems like a symmetrical and patient engaging feature about the technology might also enable and support the patient in not becoming particularly knowledgeable about the numbers, which the statements made by the patients above suggested. If the intention is to make patients more knowledgeable through actively giving responsibilities to them, the design of the Suitcase has ambiguous potentials for doing so: Ambiguous because some of the participants actually do incorporate measuring practices into their everyday life after the study has ended and the suitcase has been removed. These participants continue the practice of weighing themselves daily in order to monitor the possible accumulation of water in their body – something they have learnt from the consultations, may indicate problems with the regulation of the medication that they continue to take as chronic heart failure patients. During the course of treatment patients have grown familiar with the practice of weighing themselves (had they not already been because of repeated weighing through their life course). Through the consultation patients had been told when and why they should measure their weight, and they had done it repeatedly along with the other measurements of ECG and blood pressure. In this way measuring has become a new way of knowing their body themselves (Mol, 2000) and the domesticated bathroom scales have been reappropriated from something producing knowledge about body size to a tool for producing knowledge about the effects of a specific medication. So while the patient suitcase and the other measuring devices are removed from the home, the bathroom scales which preceded the arrangement and remain behind make it possible to retain in everyday life one of the practices introduced with the patient suitcase.

Looking at the arrangement of the virtual encounter, we have seen that the introduction of telemedicine involves a division and sharing of work and moreover demands the development of new skills from *both* patients and professionals. The patients may continue to use these skills in relation to their management of their illness after the telemedical technology is taken away – in this case with the reappropriation of the bathroom scales. Still it is important to recognize that the care a person exercises – for him- or herself or for others – is never independent of the kinds of infrastructures that contribute to this care (Danholt & Langstrup, 2012; Langstrup, 2013). What it is to be a chronic heart failure patient and which skills to acquire and activities to engage in, is definitely shaped by the distributed arrangement which includes the patient suitcase and part of the arrangement and the acquired skills may even continue to exist after the telemedical technology has been dismantled. But at the same time the virtual encounter does not seem to be best understood in terms of radical changes implied in the normative version of ‘Patient 2.0’ that suggest patients to become independent and self-managing. As far as it makes sense to label these patients as ‘Patient 2.0’ this consists in having learned about their chronic heart condition and how to deal with that – not by themselves but rather in close cooperation with health professionals that they expect to instruct them and interpret the results of their shared work. As the virtual encounters are discontinued together with delivering the suitcase back to hospital many of the skills acquired become redundant.

### ***The room in the room***

In the interviews patients and professionals alike recounted the virtual clinical encounter as being in a sense ‘the same’ as a visit to the clinic – now they just do not have

to travel to the hospital (something which all patients appreciate immensely). As we have already suggested above, it involves particular skills to establish a virtual space in which the patient and the professional 'meet' and achieve this virtual co-presence (Roberts, Mort & Milligan, 2012). Also, it may be experienced as intimate and affectionate rather than 'cold' and dis-embodied, something that has also been found in other studies (Roberts, Mort & Milligan, 2012; Pols & Moser, 2009; see also Mort & Smith, 2009). Moreover, both parties described the atmosphere of the consultation in spatial terms, as 'a room' where they could be together. The nurse said:

...you get the impression, that this is the kind of room where only the two of us exist... they have me in their living room, or in the office or where ever I am, and I have them on the screen and in my headphones. And then, in that sense, it is a closed room... (Interview with project nurse, 2010)

Her statement reflects that she experienced a clearly delimited space, where only she and the patient had access. A patient said:

... We felt we were in the same room... you know, that's how you feel... (Interview with patient, 2010)

So not only was it a closed room, it felt as if they were physically together in the same room. Furthermore, the spouse of the above quoted patient had witnessed several consultations from a chair in the background in the living room and he added:

... well, it seemed quite as if they were together. (Spouse, at interview with patient, 2010)

From these statements we see that the consultation configures a closed room, in which the nurse and patient can be together. Apart from demonstrating that intimacy may be achieved in a virtual co-presence, this also draws attention to what is obviously not the same in this encounter compared to other clinical encounters in medicine. This difference has to do with the emplacement of the virtual encounter in a wider set of spatially enacted relations. The fact that the virtual encounter *takes place* in the home (and the clinic) is not inconsequential. It is a room established within another room. When the husband above comments that he senses a space emerging in his living room through the consultation, this implies that he is positioned on the outside as a spectator. This inside-outside observation implies that the emerging room has boundaries, telling us that the work related to the consultation is also a kind of boundary work demarcating 'the room where they could be together' from the rest of the home – and from the hospital. Here we find an interesting paradox arising in which the virtual consultation is both 'the same' as any other clinical encounter between a health professional and a patient and at the same time unarguably different in that it is taking place in the home of the patient.

### **Emplacing telemedicine in ecologies of care**

Until now we have focused on the establishment of the virtual encounter and the extent to which this may be said to change patient roles or not. However, as the above section has pointed toward, the virtual encounter is taking *place* spatially in the home. Through the use and manipulation of available spaces and resources (de Certeau, 1984) the virtual encounter in these cases becomes a meaningful place for the sharing of work in relation to care. As noted earlier, place-

making is a continuous achievement and a physical, geometrical space may be different according to different uses, interpretation and times (Tuan, 1999). However, as we will see more clearly now, the accomplishment of a particular room, demarcated from the surrounding room – the home – may be a fragile accomplishment. This fragility and sometimes ambiguity of the boundaries relates to the very same resources involved in its establishment. The home is not just a geographical site, but rather in itself a situated and meaningful place we inhabit and share more often than not with spouses and other close relations (see Langstrup, 2013 for a discussion on the meaning of home in chronic illness). Relatives and spaces are part of the resources that need to be used, managed and sometimes manipulated for the infrastructure to work and the virtual encounter to emerge. So, even if it is possible to create a discrete ‘room’ in which the shared work of the consultation takes place, this accomplishment involves the activities – directly or indirectly – of other actors inhabiting the home (Langstrup, 2013). Although it was a precondition for entering the study that patients were able to handle the Patient Suitcase and carry out the associated tasks on their own, it was not uncommon that the spouse took part in the consultation. Typically, the spouse would assist at measurements by putting on the cuff or turning the switch. In one instance, the assistance of the spouse was urgent as the patient was paralyzed on one side of her body and another had a hearing impairment. Under these circumstances, enrolling relatives strengthens the infrastructure, because they become participants in the shared work involved in the virtual consultation. One patient recounts:

...then Gertrude [the wife, ed.] stood and orchestrated the events and pushed the buttons and what not... (Interview with patient, 2010)

In his account the wife almost took over the central activities of the consultation, but later in the interview he also suggests, that after some time, he did most of the tasks himself.

But relatives are not always allies in the establishment of the virtual encounter. They might have other goals than the health professional and/or the patient. For example, the wife of a patient had reacted very adversely to the nurse’s suggestion during a consultation that, to make easier to stop smoking, the patient could consider asking his wife to stop smoking together with him. The wife, then, had sworn, ‘*you can forget about that!*’ from somewhere in the living room (in a place where the nurse looking at her monitor could not see her).

So even if it may be possible to achieve an intimate room, this room may be quite fragile due to its emplacement in another room – the home – and the relations, emotions and meanings implicated here. The nurse reflects on the difficulties of handling un-cooperative relatives:

Nurse: ‘I felt like telling him to do it [the tasks involved in the consultation, ed.] himself, but in the end it worked out. She wasn’t there anymore.’

Interviewer: ‘But you didn’t have to say anything?’

Nurse: ‘No, I didn’t say anything, because I can’t really interfere when this is their home [...]’ (Interview with project nurse, 2010)

The examples illustrate how the patient suitcase and the virtual encounter may both depend on and become challenged by the actors already residing in the space in which this healthcare practice is to be emplaced, that is in the home. Thereby, healthcare practitioners may become acutely aware of the wider context in which the consultation, and more broadly speaking treatment, is

taking place. Cooperative work is – whether computer supported or not – shaped by the places in which the work is done: a point well-recognized in CSCW (Harrington & Dourish, 1996; Dourish, 2006). But what may need to be learned from this case and others on the emerging care-infrastructures that mobilized the home as a central node in treatment is that cooperative care work which involves patients and relatives at home is different from work involving actors in different, distributed professional settings. The virtual encounter may be seen as a corporate space rather than a private space, as a dyadic focus may have otherwise mislead us to believe (May, 2007). But, trying to find its place in the home the virtual encounter is faced with the unruly actors and multiple agendas of everyday life that may have been kept out of a physical visit at the clinic – though rarely out of treatment as such (Langstrup, 2013). The wife in this situation is simultaneously implicated in establishment of the virtual encounter as an actor in the home, and ‘other’ to it as resisting the effort to include her in the clinical room. Home may be seen as ‘a material and an affective space, shaped by everyday practices, lived experiences, social relations, memories and emotions’ (Blunt, 2005; Langstrup, 2013). The virtual clinical encounters in telemedicine literally have to be fitted in, meaningfully, with other kinds of practices and encounters in this ecology. The skills – or tactics, as de Certeau might call them (de Certeau, 1984) – demanded for this, are not inscribed in the technologies in question. Furthermore, the emerging room, that we have seen, may not be there all the time. It comes into existence through the shared and distributed work of consulting through the Suitcase. So while others describe telemedicine as potentially intrusive of the home (Fisk, 1997), our study indicates that work related to telemedicine is *not* necessarily continuously made part

of the home and the life led here. As also López and Sánchez-Criado found, the boundaries of the home are not given, but rather continuously negotiated and enacted in relation to the specific socio-material practices found here (López & Sánchez-Criado, 2009). Still, the home is made available at times, by technology, patients, spouses, as a place that can become reconfigured as a part of the corporate ecologies of care, which seeks to make individual illness trajectories into problems that are manageable for corporate entities, such as healthcare authorities (May, 2010). And as a place that have other identity shaping and preserving functions (Douglas, 1991), both for the patient involved in virtual encounters and for spouses and other relatives for whom this space is home, it may impose new challenges and complexities into corporate ecologies of care. In that sense, technologies like the Patient Suitcase not just giving responsibility for care to the patient but rather – by re-distributing the shared work on more actors and emplacing healthcare in the home – introduces more complexities to be managed as part of both healthcare workers and citizens having these technologies introduced in their homes.

## Conclusion

Telemedicine is again and again promoted for its ability to ‘give back’ power to patients. Specifically in our case of the Patient Suitcase and the Tele-heart Failure project, patients are suggested to learn to care for themselves and become more independent of medical experts. But as our analysis of the collaborative actions of the health professionals, patients, relatives and technology involved in the virtual clinical encounter has shown us, the Patient Suitcase does not take work, knowledge and power away from one actor in the

clinical encounter to give it to another. Both patient and health professional acquire new skills through their different usages of the patient suitcase. It is notable, however, that the patient users of the Suitcase find the health professional to be the manager of the virtual encounter and the interpreter of data, while they find themselves to be authorized to do practical tasks. Some of these tasks and the skills associated with them obviously become obsolete when the technological setup and thus a major part of the care infrastructure is dismantled and the Suitcase travels back to the clinic. We may only speculate if a different kind of telemedical equipment or a different sample of participants (younger or better educated) would have resulted in more profound changes as to their engagement in their medical treatment. We would welcome more studies on these questions as the rising market for self-diagnostic tools and monitoring do suggest that some favour a more patient-led demand for health services. What constitutes a patient is however highly contingent on the infrastructures of care and their durability and specific to the present case is that work was highly shared in the virtual clinical encounters. All the while the arrangement of the patient suitcase was in place the technology demanded cooperative efforts – also efforts concerning making the virtual encounter a meaningful place within an existing place – namely the home. We have argued that emplacing the patient suitcase in the home – making a room in a room – demands continuous sharing of work, development of new skills and involvement of at times unruly actors. Decentring our view and looking at the place-making involved in setting up and sharing work in the virtual clinical encounter may make us more alert to the demands put on patients, professionals and relatives to manage the at times diffuse and ambiguous boundaries between the place established for sharing the work and the

place of the home, which may have many other functions in terms of developing or preserving the inhabitants' sense of self. For it is not at all obvious precisely where the clinical encounter starts and the home ends, or where the patient role begins and the other and potentially contrasting or conflicting roles and responsibilities end. The notion of Patient 2.0 – even if by nature of its numbering encompasses networked technology – does not give many clues as to these new challenges in managing relations between place, self and other, as it has a tendency to make us look at the level of the individual when searching for effects of new technologies in healthcare. But as May has argued, 'the clinical encounter itself is only one part of an assemblage of complex organizational, institutional and disciplinary resources and practices, in which units of analysis are to be found at diverse organizational interfaces – and where subjectivities are constructed and worked out in multiple and diverse ways in relation to new managerial technologies' (May, 2007: 41). Emplacing the 'managerial' technology of the Patient Suitcase in the homes of patients creates such new interfaces with possible implication for subjectivities for all those involved – whether they are patients, health professionals or relatives. But in terms of getting a better understanding of what changes telemedicine implies, we may get more interesting insights if we decentre our attention from the individual patient – 2.0 or otherwise – and look at the implications of distributing the management of healthcare on more actors, technologies and places in corporate ecologies of care.

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