The Ecology of Care in Cystic Fibrosis

Identification, Decision-Making and Learning in a Community Living and Working with a Rare Chronic Illness

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Abstract This paper sets out to describe how developing an identity as a member of a community organized around a rare chronic illness and becoming knowledgeably skilful in mastering the challenges of decision-making are part of the same process. We examine a community living with cystic fibrosis (CF) and their care-givers. CF is a rare inheritable disease with a chronic life-shortening course. Today, the growing complexity of care, with the resulting longevity for people with CF, governs the practicalities of day-to-day decision-making, highlighting an increasing need for interdisciplinary collaboration. Building on long-term ethnography as anthropologists and physicians, we use a practice theoretical approach to explore in a highly specialized university medical centre how patients and care-givers make decisions and negotiate meaning, and their position, within such a community of practice (CoP). Drawing on ideas from distributed cognition and knowledge-practices, we show that the CF CoP is characterized by three interrelated elements: First, by the development of a shared identity around the question how to manage and live with a rare chronic illness. Irony is used in establishing a position both outside the dominant mainstream of medicine and outside the dichotomies healthy/ill. Second, managing the condition requires collective learning in the domains of everyday life and clinical decision making, cutting across established status groups of patients and caregivers. Third, by taking experience and learning out of the individual's head and making it a procedure to be enacted in similar moments, we argue that the embodied-knowledge of prior generations is not passed on but regenerated within the contexts of novices' interactions within the social and material environment. Together, the three elements create a collectively embodied-memory culture allowing the CoP to regenerate itself and adapt within times of rapid change.

Keywords cystic fibrosis – chronic illness – communities of practice (CoP) – distributed – decision making – knowledge-practices – Germany

Introduction

Since its publication over 50 years ago, "The Ecology of Medical Care" (White, Williams & Greenberg 1961) has provided a framework to think about health-care organization, medical education and research. Its conceptualization of medicine as a social institution was inspired by diary studies and careful reporting on the part played by general practitioners. Its ideas on the stages of decision-making, when patients and their health advisors, "whether physicians, pharmacists or faith healers" (*ibid.:* 188) seek help and consultation from other medical-care resources, these ideas have resonated widely in medical literature and have found their way into textbooks and articles (Eddy 1990; Haynes, Devereaux & Guyatt 2002; BATTEGAY 2005; Saint, Drazen & Solomon 2006; Mark 2008). Yet, its focus on *applications* of medical expertise in complex institutional settings falls short of recent advances in the anthropology of knowledge and the challenges of those advances to medical anthropology (Beck 2015, Cohn & Lynch 2017). Additionally, the ecology of care may look quite different in the 21st century's highly specialized medicine and may not capture the dynamics of care under reformulated concepts of health and doctor-patient interactions.

One of those dynamics, pointed out by Clarke *et al.* (2003) is the increasing focus on biomedicine, technology and the relentless marketization of health for better or worse. With it came a growing interest in the concept of care in nursing theory and the social sciences (ROBINSON 1998; MOL 2008; MOL, MOSER & POLS 2010). Another development, discussed by DUMIT (2012: 6) is a paradigm-shift in the understanding of health and illness. Since the 1990s, the paradigm of "inherent health" and illness as a deviation from the norm was replaced by a notion of illness, in which bodies are inherently ill. A precarious-self arises which needs constant maintenance to keep symptoms at acceptable levels. These shifts have been accompanied by the growing acceptance of new concepts in doctor-patient interactions, such as "shared decision-making" and "empowerment" in medical practice. These models assume that patients are willing to and capable of making decisions about their health with their health-care providers (RAPPAPORT 1981; CHARLES, GAFNI & WHEELAN 1997).

Social scientists have undermined the cognitive framing of these health-related decisions in attempts to reframe decision-making as "distributed." The temporality of decision-making has been stretched from discrete moments of cognition to being incrementally built over many instances of time, place, and contributors (HUTCHINS 1995, RAPLEY 2008). Over the last decades, medical anthropology and sociology have benefited tremendously from debates leading to the current understanding of the distributed agency of patients and healers. The discipline moved from the recognition of patients as individual and collective agents who have a voice in conflict with the professional or physician (DAHRENDORF 1958, FREIDSON 1970, ILLICH 1976), to the idea that this agency is not a *given* but comes into being, mainly, through non-compliance (LOCK & KAUFERT 1998; GREENE 2004), and how this develops over time in a "dance of agency" with health-care providers (PICKERING 1995; CHARLES, GAFNI & WHEELAN 1997; GAWANDE 2004). In recent years, the debate has widened its focus towards the question of how agency might be understood as an emergent effect created through alliances, connections and networks. These are now understood to involve humans and texts (GABBAY & LE MAY 2004), material artefacts and technologies (PROUT 1996), other species, including domestic and research animals (HARRAWAY 2008), and relations of power and social positioning through which individual and collective agents in the health-care system are enabled or hindered in exercising influence and change (CALLON & RABEHARISOA 2008).

We would like to extend the understanding of decision-making one step further by drawing attention to the process of *becoming part* of this collective agency or community of practice (CoP, WENGER 1998). A broad definition of a community of practice is "a group of people who share a concern for something they do and learn how to do it better as they interact regularly" (WENGER 1998). The shared learning becomes a bond among the members over time. Over the last decades, CoP has become an important concept to understand social learning and knowledge integration. Originally, it was developed to understand adult learning in apprenticeships *e.g.* midwifery (LAVE 1991). Today, its use has been extended from learning *within* to learning *across* disciplinary communities in science, businesses, and medicine (REGEER & BUNDERS 2003; AMIN & ROBERTS 2008; MANIDIS & SCHEERES 2013; CUNDILL, ROUX & PARKER 2015; CRUESS, CRUESS & STEINERT 2018).

A key concept of CoP theory is that one becomes a member of a community by acquiring the skills and knowledge of that community; with this, one moves from legitimate peripheral participation to a more central position, transforming oneself as well as the group (LAVE & WENGER 1991). Sociologist MERTON has been a pioneer to point out the dual nature of medical education, whose aims are to provide those wishing to become physicians with the knowledge and skills necessary for the practice of medicine and a professional identity so that they come to think, act, and feel like a physician (MERTON 1957). Medical educators (PARBOOSINGH 2002, CRUESS *et al.* 2014; CRUESS, CRUESS & STEINERT 2018) have recently taken up this view of learning, practice and professional identity formation as inseparable.

Social scientists caution us that the growing disciplinary specialisation and division of work would "truncate both the movement from peripheral to full participation and the scope of knowledgeable skill" (LAVE 1991: 65). In specialized medical settings like emergency rooms, it has been suggested that practice knowledge is tied to CoP member's professional identities and the acceptable ends as defined by practical intelligibility. Learning then would largely be confined to "particular knowledges" and "particular relationships of learning" (Manidis & Scheeres 2013: 15; Creswick, Wesbook & Braithwaite 2009: 6), separating identity from intended forms of knowledgeable practice.

This paper sets out to describe how developing an identity as a member of a highly specialized community organized around a rare chronic illness and becoming knowledgeably skilful in mastering the challenges of decision-making are part of the same process. We show that managing this illness requires mobilising and coordinating the CoP's distributed elements and collective learning in the domains of everyday life and clinical decision making, cutting across established status groups of patients and caregivers. The development of a shared identity related to the condition and the care of patients are sustained by temporalizing collective learning. This is achieved by taking experience and learning out of the individual's head and making it a procedure to be enacted in similar moments. The embodied-knowledge of prior generations of patients and staff is not passed on but regenerated within the contexts of novices' interactions within the social and material environment. Instead of creating unrelated, particular knowledges, the members of the CoP create a collectively embodied-memory culture, allowing the CoP to regenerate itself and to adapt within times of rapid change.

Field research in highly specialized clinical medicine

The theoretical framework outlined above has implications for research methodology. Although participant observation is central to anthropology's methodology, rendering its understanding and the kind of claims it makes about the social world (Clifford & Marcus 1986, Jorgensen 1989), it has rarely been used as a means to expose the emergence of a knowledge-practice, like decision-making and identity formation in postgraduate clinical practice in relation to the anthropologist as subject. A few notable attempts are Hunter's (1991) detective-like exploration of the narrative structure of medical knowledge, Katz's (1999) illustration of the culture of surgeons and the active stance in surgical decision-making, Luhrmann's (2000) analysis of how psychiatrists learn to understand people as they do and Risor's (2012) study on how internal medical-residents evolve to think like doctors.

While these studies, which describe medicine as a culture or subculture and frame their analysis in terms of enriching and fascinating rituals to read about, they are limited or rather shaped by the authors' interpretation of their own roles, as at least semi-detached participant-observers. Most of the above-named authors are excluded, for lack of professional skills and qualifications, from a more active role.[1] Yet, we believe there is something to be gained by living up to anthropology's aspiration and committing "body and soul" to the practices one longs to understand (Wacquant 2004, Myerhoff 1978). We interpret anthropology as an entangled material-semiotic process of learning and knowing (Suchman 1987) that benefits from participation in the practices one observes (Mol 2002, Law 2004). We like to think of this research, both, as a process of becoming part of a community and of *becoming with* our research partners, or, as Ingold (2013) might phrase it, to learn not about our research partners but with and from them.

We use a practice theoretical approach, where practices are understood as a set of sayings, doings and being organized by a pool of understandings, a set of rules and teleo-affective structures (Schatzki 2001: 61). Identity (of a person or learner) and meaning (of a procedure or an artefact) are conceptualized as functions of its relations and conversely, relations are functions of its meaning/identity (*ibid*: 51). This is important, as it allows to look beyond fixed social roles (physician, nurse, patient), and to foreground the relational nature of identity and practices: People perform acts of caring, healing, deciding, swallowing pills, inhaling, writing up cases, telling stories, and through these performances work on identifying as doctors, nurses or patients. Processes of identification are shaped by the practices people perform and the relations with other people that arise within these practices.

The present work is part of a long-term ethnographic study on the practices of everyday-life with chronic illness (Reinsch 2013; Reinsch & Rascher 2015; Reinsch, Niewöhner & Staab

2016). It draws on interviews and field-notes, collected by the first author over two one-year periods in a German university medical centre specialized in CF care. The first period, 2006–2007, was part of a MD-PhD research. The second period, 2016–2017, took place during residency training in paediatrics while working on the CF ward. In between, several short-term research periods and follow-up interviews took place.

According to LATOUR (2004) and GARFINKEL (1967), field research proceeds by following the actors to explore and map the distributed networks of encounters, people, technologies, practices and decisions. We followed the principles of Grounded Theory that emphasizes the procedural and iterative nature of research where data collection and analysis proceed simultaneously (CHARMAZ 1983, CLARKE 2005).

Participant observations were recorded with field notes and later digitalized (JORGENSEN 1989; EMERSON, FRETZ & SHAW 1995). Informants were followed in their clinical and daily routines. Half of the research took place inside and the other half outside the hospital. The auto-ethnographic part of this research introduces accounts where the first author documents ways he changes as a result of working and doing fieldwork (ELLIS 2004). In using personal experience, auto-ethnographers are thought to use supposedly biased data (ANDERSON 2006). To address this critique, auto-ethnographic accounts were analysed alongside data, abstract analysis, and relevant literature (ELLIS, ADAMS & BOCHNER 2010), as well as conducting interactive interviews and focus-groups.

Narrative and interactive interviews as well as focus group sessions were used to probe in-depth into views on specific topics and contextualize cases or situations. They were held in the clinic or at home of informants, audio-taped and fully transcribed (SPRADLEY 1979). Interactive interviews were collaborative endeavours between researcher and participants, in which both reflected and probed together about issues and problems (ADAMS 2008). Focus groups were started by presenting the participants with visual and anecdotal material from the field research. Participants were asked to comment on the material, explore similarities and differences to their own experiences, as well as discuss rationales, legitimating strategies and emerging concepts (MORGAN 1997).

Conceptually, interactive interviews and focus-groups were attempts to collect new data, but also create experimental interruptions within the research process, with the intent of staging reflexive encounters between research partners (BOYER 2015). Within those reflexive encounters, emerging categories and mind-maps were discussed with medical and anthropological experts as well as patients. Additionally, triangulation and member checking were used to validate findings. Research continued until theoretical saturation was reached, i.e. no new concepts emerged after subsequent data collection.

The study was approved by the internal review board of the university hospital. After receiving oral and written information about the research project informed consent was obtained from patients. To protect the identities of participants, pseudonyms have been used throughout the research for all informants.

The ecology of care in cystic fibrosis

We describe a CoP organized around a chronic illness that is characterized by the development of a shared identity around the question *how to manage and live* with a rare chronic illness while undergoing a rapid demographic transition. This special status, a rare condition during a time of transition, requires collective learning in the domains of everyday life and clinical decision making, cutting across established status groups of patients and caregivers.

Two empirical examples are used to present the argument. The first examines the story of one of the oldest patients with CF and the history of the CF centre where she is treated. We show some consequences of growing old within a CoP organized around a rare chronic disorder and the practice which reinstates the membership in this community, including how difference can be transformed with the use of irony to create a position outside the dichotomy ill/healthy, as well as the mainstream of clinical medicine.

The second example uses an auto-ethnographic account from the first author's perspective as a physician, peripheral to the CoP, while learning to manage a critical situation in real-time, during a night shift. Here, we've focused on the question of how the distributed-actors and elements of the

CoP are mobilized in order to manage such a situation as well as the role of experience and the temporal component of the situated-learning process.

We will, thereafter, discuss some implications for the ecologies of care in highly specialized medicine, and the anthropologic role in these communities.

The community of practice organized around cystic fibrosis

Mrs. Monk is one of a number of people with CF (PWCF) who are, regularly, admitted to the hospital for exacerbations of their chronic pulmonary infection. In PWCF, the defensive mechanism, the removal of bacteria through mucociliary clearance, is impaired. As a result, PWCF suffer from chronic infections. To compensate, the other defensive mechanisms, coughing and inflammation, are up-regulated. Jointly, they lead to progressive destruction of functional lung tissue by chronic inflammation which lead ultimately to lung failure, requiring long-term oxygen therapy and, later, a lung-transplantation in the majority of people (BOUCHER 2008). In severe acute exacerbations, the number of bacteria in the airways is overwhelming, requiring treatment with a combination of intravenous antibiotics.

> On Monday morning, word has spread that Mrs. Monk was flown in by helicopter from a vacation at the Baltic Sea. During handover in the emergency room, those who do not know her already get to know her by anecdotes, told in amazement, about having a lung function of below 20 % but still working; although, she needs continuous oxygen supplementation, and, the voices turn to an exited whisper when they come to this part, that she is working several hours without using her oxygen. She is a little celebrity among the group of young doctors assembled that morning in the hospital. The reasons for this are not only her personal defiance of age and decay, but also the changing demographics of people with CF in general, of which she is an exceptional example. (Field notes)

Over the last few decades, there has been a steady increase in survival rates for those affected by CF. Today, half of the population living with CF in the US and Germany is over 18 and the predicted age of survival is still rising, enabling more and more of them to enter higher education, work and start their own families (CYSTIC FIBROSIS FOUNDATION PATIENT REGISTRY 2017, MUKOVISZIDOSE E.V. & MUKOVISZIDOSE INSTITUT 2017). No single new drug is responsible for this but a very complex therapeutic regimen that the patient has to perform at home, daily, requiring some two hours, and including up to seven medications and a more comprehensive care-team in highly specialized CF centres (SAWICKI, SELLERS & ROBINSON 2009, DAVIS 2006).

The CF centre where Mrs. Monk has been treated in excess of a decade is an integrated children and adult service, caring for 350 PWCF. Called the “Christiane Herzog Centre,” in memory of a former German president’s wife, who’s foundation helps raise funds for CF research and care, the center is one of Germany’s four largest centres of this kind. Administratively, it is part of the Department of Paediatric Pneumology, Immunology and Intensive Care Medicine of a university hospital. It grew out of a lung clinic at the outskirts of Berlin where, primarily, tuberculosis (TB) patients were treated (LODDENKEMBER 2007). As TB became less common, funding for TB treatment was decreasing, and people with cystic fibrosis became older, the unit caring for CF became the clinic’s central focus (MAGDORF 2007, STAAB 2007). This shift was later accompanied by moving the CF centre to the university campus, located more centrally and part of a complex that includes the German Heart Centre, specialized in organ transplantation.[2]

The centre’s staff caring for PWCF before and after transplantation is comprised of seven physicians and around 40 nurses, two psychologists working half-days plus one adjunct-psychosomatic doctor who join the team once or twice, weekly. Three physiotherapists, two dieticians and a social worker also assist. The centre is led by two heads, a paediatrician and an internal-medicine specialist, both specializing in pulmonology. The two are consulted on every case and lead rounds between three-to-five times a-week, with alternating weekends. The other half of their time is spent in the out-patient clinic with routine check-ups, follow-ups and research. One attending does the routine ward work with four residents-doctors, some of whom are in the middle of their sub-specialization in pulmonology. The remaining junior-residents are in the middle of their general paediatric training. The residents rotate to different wards every six-to-twelve months. They are sometimes called “six-months-doctors” by the patients, in contrast to the “real” CF physicians, like the centre’s heads or the nurses and psychologists who sometimes know the patients from diagnosis, often from the patient’s birth.

Participating in a CoP means partaking in its continuous reproduction

During morning rounds the day after Mrs. Monk’s admission, the following discussion between Mrs. Monk, the attending-physician, and one the CF centre heads, takes places:

> Mrs. Monk: The emergency doctor in the helicopter asked me “How old are you? You cannot have CF. People with CF are all dead by your age.”
>
> Attending: You should have given him an autograph.
>
> M: Many doctors ask me “when did you get CF.”
>
> A: Also, very popular: “how long are you going to have it?”
>
> Mrs Monk laughs, her voice is hoarse, and she is short of breath, but eager to tell her story: When I was 25, my doctor told me “You are the living miracle in Methuselah’s age. You should be long dead, are you aware of this?” – “No,” I responded.
>
> A: You should show more understanding for them; they were all listening carefully during the lectures in medical school.
>
> The clinic’s head, interrupts: It is a problem though, that it is assumed one wouldn’t get old with CF. Those with CF who are 30 and have no plans for life are now becoming depressed.
>
> M: That, I have never been told. My paediatrician told my parents: “Treat her like a normal child; she will live to a normal age.” It did not hurt me.
>
> C: The oldest patient here is 73.
>
> M: Yes, I saw her walk down the ward, without oxygen. That made me jealous.
>
> C: She also has a mild version of CF.
>
> M insists, looking around her: I would like to do that too, get loose from all these strings.
>
> C: You want to dance without oxygen.
>
> M: That I cannot do anymore even with oxygen.

Mrs. Monk is sitting in her bed, upright, breathing hard, supported by oxygen through a high-flow nasal cannula. Resulting from her years of constant inflammation, her airways have lost elasticity and, now, with her chronic infection getting worse and her sputum building up, her airways would collapse without the positive-pressure of 60l of air, blown into her lungs to keep them inflated and to allow her to breathe at all. She has two intravenous (i. v.) lines through which antibiotics and other medications are injected into her bloodstream, through a port catheter. The port is implanted under her skin, so she does not need to get i. v. catheters set every-other-day. Setting a new line has become difficult over time, since frequent i. v. antibiotics courses cause inflammation in the veins while the superficial-veins, which are easy to puncture, become thinner and then disappear. The inhalation medications and pills on the table beside Mrs. Monk are an assembly that would be poly-pharmacy for anyone. Among them are inhalations of saline to make the mucus less thick, and bronchodilators and corticoids that she has to inhale several times, daily, to reduce the inflammation. There are pancreatic enzymes in a pillbox to help digest food, vitamin replacements to compensate for malabsorption and stool-softeners to prevent intestinal obstruction.

Before the physicians and nurses enter her room, they have gone over the list of therapies and adjusted a few up or down. However, the therapeutic adjustments are not what is at the centre of today’s discussion. In the middle of her fifties, Mrs. Monk is the second oldest of the centre’s 350 patients, a fact for which she is quite proud. Old age is uncommon for people with CF and people like Mrs. Monk do not fit the stereotypic imagery of someone with a rare progressive genetic illness, where, adolescence was the unsurpassed median age until a few decades ago and which usually lead to death, by lung failure, that is: suffocation.

Faced with the doom of an exacerbation that could have led to fatal lung failure, Mrs. Monk and the two physicians are attempting to create a meaningful narrative out of the apparent amazement over this new CF old age phenomenon, not yet anchored in mainstream clinical-medicine. Mrs. Monk and her physicians have collaborated for years to defy the odds, as they are reminded by the emergency-physician. He, like many physicians, did listen attentively during lectures but, nonetheless, is unfamiliar with the developments in CF medicine after medical school graduation, as the attending doctor jokingly remarked.

On one level, the conversation does not have any medicinal relevance and could pass as unnecessary gossip. On another, however, the question arises, why are those three so eager to share this story on a Monday morning, in a crowded ward, with a clinic full of patients waiting to be seen? The functional aspect of this discussion can be located by being able to partake convincingly, in bashing other medical practitioners. Accordingly, the group assures itself that it is a valid member of a specific CoP, i.e. a community that is experienced and competent to deal with CF. As Wenger (1998: 74) reminds us, it is just as important to be a full participant in a CoP to understand the latest gossip as it is to understand the latest medical paper or innovation. The gossip excludes the emergency physician and all the others who do not know that people with CF are asked, repeatedly, "When did you get it"? Conversely, the bond between doctors and patients is reinstated through shared gossip, based on their personal experiences with the condition. It is noteworthy that membership to this CoP runs across established status groups, including experienced long term "chronic" patients, while excluding physicians without specialized experience and competence in treating CF. While this has been discussed for other contexts of chronic disease, *e.g*. ADHS and Alzheimer's Disease (Rabenarisoa, Moreira & Akrich 2014), it occurs in a particularly pronounced manner in this context.

Herein, the CF community differs from communities with a shared identity that excludes them from the "normal ones," like the hard of hearing and those professionally related to them, as analysed by Goffman (1963: 30) and others. Their shared competence or expertise resulting from shared experience and learning, rather than their stigma distinguishes members of the CoP from outsiders. We will return, later in the paper, to the question how physicians peripheral to the CoP make the necessary experiences to move to full participation in the CoP.

Living-attached in a world of compulsory able-bodiedness

Only after the group of physicians has assured itself of its membership does it turn to the challenging aspects of living with CF: People who did not believe they would live to be 30, then, become depressive by a lack of plans or they might live a life with work, family and vacations at the Baltic Sea, like Mrs. Monk; yet it is tiresome. It, simply, is living attached to lifelines (lines that keep her alive and part of the social life), lines made of oxygen, i. v. medication, delivery systems, physiotherapists who come to her place regularly, the very infrastructure of CF care. Living-attached may be without choice but the group knows how tiresome it is to be reminded that, with all that constant work to keep the CF symptoms at acceptable levels, "even with oxygen", the most existential of all medications, "one cannot dance, lightly, anymore" through life.

By alluding to the impossibility to "dance through life", Mrs. Monk and the attending are speaking of a life that is different from bare life or survival. Survival being what is assured through those very lines. What the two are talking about is life itself where life is conflated with a social life – "life as we know it" – that is threatened by the existence of the lines that attach her to the therapeutic infrastructure.

While almost everyone is able to at least *walk* through life without oxygen—that is, exempt for extreme places as on top of the Everest or under water—Mrs. Monk is not able to survive long enough in the social habitat of Homo sapiens. She is as a fish out of water or rather a human under water, making it is impossible for her to live *effortless and comfortably*.

In one of our discussions, she relates how living and working among people that look at her with less respect when she does wear an oxygen mask is exercising a repetitive effect which made her take off the mask: "People already look queer at me when I walk down the corridor to the courtroom with my mask on. They respect me less when I wear one, so I take it off during the trials."

The dilemma of disclosure at the workplace for people with potentially "invisible" chronic illness and the threats to emotional and physical wellbeing has been discussed for many conditions (Vick-

ERS 1997). What is striking in Mrs. Monk's example is that the place she takes the mask off is one where she is in a position of power. A family judge, she is, nominally, exercising the authority of the state during court processions. Yet, these are the situations when she will work several hours without supplementary oxygen.

The repetitive effect of being looked at queer with a visible difference makes her feel uncomfortable. As AHMED (2004: 148) put it, to be comfortable is to be at ease with one's environment that it is hard to distinguish where one's body ends and where the world begins. Attracting queer views repeatedly when wearing an oxygen mask is leaving impressions that made her aware of her difference.

Mrs. Monk is made aware that she is living in a world were able-bodiedness, health and happiness are presented as an ideal coupling. The accumulative effect of the repetition of this presentation of able-bodiedness, health, and happiness as an ideal coupling, and the questioning of her presentation shapes what is comfortable for people like her to do.

In retrospect, Mrs. Monk subscribes to this tight woven narrative: "Every step, having to use intermittent oxygen, later continuous oxygen and, now, non-invasive ventilation overnight, were always steps in the wrong direction … You cannot get off oxygen anymore; using it is a sign that it is going in the wrong direction, worse, not better."

Like Mrs. Monk, many PWCF that have less of a position of power, struggle with this feeling of being uncomfortable in the world. One of the adolescents we talked to told us he would never have imagined to take oxygen to school. He said he would not even let his friends carry his schoolbag upstairs when he was already huffing and puffing on the flat surfaces: "My body didn't thank me though." A young woman in her thirties reflected, that she was going on vacations with friends to the Netherlands, and only there, where no one knew her, would she start feeling at ease with the oxygen tank in public.

In the following section we will turn towards the question how this difference can be embraced and taken on via collective action where the uneasiness is not negated but transformed, creating a space outside the uncomfortable dichotomies healthy/ill.

Identification and use of irony in the establishment of a "position outside"

In the face of an existential crisis in medicine, narratives seek to temporally and meaningfully sequence the experience. Within such narratives, irony is one element that gives expression to the changing relationship between body, self and society, an experience which progressing illness invariably entails. BURY (2001: 278) has listed examples of irony in narratives which renders the expression of a positive view of the experience, by distancing the self through humour. We would like to highlight another dimension of irony, specifically, the element of the "insider-joke" observable in a number of examples.

One may be surprised by the amount of irony, sarcasm and laughter on the CF ward. In the exchange between the two doctors and Mrs. Monk, it reveals that they belong to the same "community of the initiated" or "the wise," as GOFFMAN (1963: 28) called them, by making fun of the emergency doctor on the helicopter and, indirectly, by relating their stories of similar events. One inside joke that circulated among the community on the ward went: "PWCF are like snails: slimy and slow," obviously relating to their lack of energy, shortness-of-breath and the sticky mucus they produce.

The quality of their sputum is something so central that patients have to learn to produce and judge it as an embodied knowledge practice or skill (HARRIS 2005, INGOLD 2013). It serves to evaluate the exacerbation severity by the coughing frequency variation, and the amount and colour of sputum. Sputum is visited like stool visits on gastroenterology wards. And similarly to stool visits, some physicians working on the CF ward, and peripheral to this community, were disgusted by PWCF letting their sputum stand in unlidded transparent plastic containers (yellow-green, with a purulent smell and sticky). In fact, so sticky, patients sometimes turned the containers upside-down to show how it clings to the bottom, holding it towards the audience to show how extreme it was.

In an ironic attempt to turn their situation into positive-value, some of the community of PWCF have developed a card-game, called the "CF Quartet." In an analogy to car or train quartets, PWCF are shown with their image and markers of their "performance": pulmonary function, lowest oxygen saturation, weight, height, and longest stay in the hospital.

In his book "Representation," the cultural anthropologist HALL (1997) suggests three transcoding strategies that people use to position the subaltern or colonial subject in the context of power and stigma: (1) "inversion of stereotypes" (2) "positive" respectively "revaluation" of images and (3) "representations-crossing by de-familiarizing and un-identifying." While we are not claiming that medicine stereotypes patients in the same manner in which mainstream society stereotypes the "Other," we believe these strategies are useful when analysing the situation of people with chronic illness. PWCF, explicitly, used the "deviance of the normal" as a quality. It can be seen as positive affirmation. Whether the winner of the "CF-Quartet" is the one with the best or the one with the worst performance is left vague; representations are not only representations *of* but also always representations *for*, i.e. they are worked with, played with and negotiated in a situated manner. A close look at the images chosen by the players shows that ironic play with one's sense of self and self-representation is the central element in undermining the dominant typologies of the ill as unattractive, invisible and unhappy.

This undermines the hegemonic imagery but not necessarily aims at modifying it. Neither do people with CF seem to aim for an approximation of their type, approaching the norm of the "healthy and beautiful." They do not even constitute a kind of CF-chic. Rather, it seems to be a variation of what STEPHENSON & PAPADOPOULOS (2006), building on Foucault's "aesthetics of existence," call "outside politics." Through ironic interactions, patients multiply the possibilities of experiencing chronic illness and the possibilities of being interpellated. The quartet circulates only inside the community of patients and care-givers. More importantly, it takes a "position outside" the hegemonic dichotomies of beautiful vs. ugly and healthy vs. ill. Through ironic deflection, a possibility of death (the unspeakable) is positioned centrally. It is a move towards an aesthetic of existence, in relation to death, that creatively transforms the meaning of CF. This move creates a space where the normalizing function of subjectification is undermined and where the possibility of freedom can exist.

Learning and decision-making in the community of practice

The same way as Mrs. Monk was admiring the 73-year-old lady who walked down the ward without oxygen, patients and physicians were talking about her: She inspires and sets an example. We want to turn, currently, to the question of how patients and care-givers within the CoP learn and make decisions in a way that helped Mrs. Monk become one of the oldest patients of the centre.

Mrs. Monk had started deviating from the beaten track, early. When the mainstay of therapy in the 1960's was letting children sleep in tents with moist oxygen-enriched air, her parents and paediatrician dissented the recommendations of the university hospital and went for a big box of inhalation in the back room of the doctor's office. Mrs. Monk had to go there several times per week. Later she was assigned one of the first portable devices—then the size of a radio—and that she used three times daily. We mention this to highlight that she was, then, already following a therapeutic regimen close to the intensity commonly used today.

Mrs. Monk never saw herself as someone with CF. She only had contact to other PWCF, briefly, in the 1980s, because all the others died quickly, one after another, at a time when she was in her twenties studying law and getting married.

There have recently been developments in CF care that correct the basic defect, the defective ion channel. Mrs. Monk had put great hope in this medication. The cautioning voices were taken stoically, that the effect of the medication was not the marginal increase in lung functioning by 1 % but rather the decrease in acute exacerbations. Just when her symptoms were under control, she sacrificed this opportunity to try out a new strategy to improve her condition. Over two weeks, we tried to increase the dosage but the medication was making her even more short-of-breath; so, the medication was ultimately discontinued.

We would like again to point out that, just as discussed around the question of membership to this CoP above, decision making runs across established status groups, including experienced long term "chronic" patients, while excluding physicians without specialized experience and competence in treating CF. In our numerous discussions, many young physician colleagues reflected how the process of decision making—central to the status of the physician—is "taken over" at least partly by experienced patients. A couple of weeks after starting to work on the CF ward, they began to talk about how they were being asked by a patient to rather take another vein to place an i. v. line, which they then found to be surprisingly attainable. We mused about patients who told us they already knew in advance that her exacerbation would not respond to a certain antibiotic, or patients pointing out an allergy to an antibiotic that was not listed in any of the charts, or those patients who preferred to speak about a certain topic with one of the attending physicians. This special relationship extends towards more experienced physicians as well. One of the most eminent CF physicians from the US, Doctor Warwick, reflects about the involvement of patients in therapeutic tinkering: "The thing about patients with CF is that they're good scientists. They always experiment. We have to help them interpret what they experience as they experiment. So, they stop doing their treatments. And what happens? They don't get sick. Therefore, they conclude, Doctor Warwick is nuts." (Cited in GAWANDE 2004)

We are not arguing that the fundamentally asymmetric relationship between patients and doctors is erased. Patients are not recognized as formal experts, no matter how much they know or experiment. Rather, patients within the CoP have acquired a situated knowledge—where to place an i. v., which physician to trust with a decision, or which antibiotic is helpful for them, and what might be a good situation to dispense with some therapies—drawing on prior experience. This specific knowledge makes them old-timers of the community.

While following the leads of such old-timers seems helpful to young colleagues that learn to trust them quickly, it also challenges the status of the physician within the CoP. One physician who had already finished her sub-specialisation told us, rather exasperated, that it took her two years to accept that "patients know it all better". Several colleagues mused that while they would be able to make decision themselves, they preferred *care-ful* ways of learning within the CoP, by which they understood being led through experiences by colleagues, nurses or patients that are more experienced.

As can be seen in Mrs. Monk's story, just as in the interview with Doctor Warwick above, adjusting medication and therapy related decision-making is a joint effort within the CoP. Likely necessarily so, as a team of specialized physicians could plausibly manage a patient's health without that patient's cooperation; this would certainly not be "good care" in the sense of MOL (2008), or Mrs. Monk, for that matter. The *shared doctoring* and *therapeutic tinkering* (MOL, MOSER & POLS 2010) links this CoP to professional knowledge and expertise.

To illustrate how shared distributed decision-making and shared doctoring extends into situations where knowledge is generated, or rather re-generated within the CoP, we propose delving into the field-notes describing a night shift where the first author had to mobilize and coordinate the distributed elements of the CoP, in order to manage an unfamiliar situation.

The night shift

In the middle of the night, around 3:30, a nurse awakened me. One of our patients had started coughing, badly, she said, and had already used all her codeine for that night, the medication that suppresses the cough. Drowsy from sleep, I walked to the nurses' station, studying the patient's chart. Two times/15 drops of codeine for the night, maximum, it stated, a dose just increased from the previous night and already used up, a dose at 11:00 pm the other at 1:00 am. I quickly calculated that if the effect of codeine got her through 2 hours, and the last dose was at 1:00, she might have been coughing for 30 min already, by the time I was awakened. This was some 5 minutes ago. I have to find a quick solution. I listened up. Down the corridor, I heard her coughing, mixed with the sound of the nurse's footsteps. She would return in 10 seconds to ask me to look at the patient, noting that it was really bad, now. I had learned that on this ward, a nurse asking you to look at the patient whom you are already working on means she wants you to hurry, without saying it explicitly. I felt the pressure building up to act. Therefore, I dropped the file and rushed down the dimly lit corridor, towards the open door from which the coughing came. As I approached, the sound became mixed with the oxygen bubbling and the CPAP machine hissing, a non-invasive mechanical ventilator. Not a good sign, I thought; in the evening, this patient was sitting without oxygen when I made my rounds to see how everyone was (a preparation, in case I would have to intervene suddenly in the night).

In the patient's room, the nurse sat at the patient's bedside, patting her back, talking her through every breath, gently. The patient held a mask over her mouth and nose (the CPAP's mouthpiece that pressed air into her lungs, after every breath, to keep her lungs open longer, and thusly, helping the patient ventilate, to exhale, to be specific). With nearly every inhalation, the patient, a young woman in her twenties, started coughing again, bending over, inhaling, gasping and coughing, again and again. "Can't we get her some morphine or Dipi," the nurse asked. I knew morphine or piritramid (the ingredients of Dipidolor) would be the next medication, an escalation from codeine. In addition, morphine would act quicker, since one fifth of codeine has to be metabolised into morphine first. It then suppresses the urge to cough in the brainstem, along with the urge to breathe. This was a CF Patient, with a bad pulmonary situation and NOT a patient to make mistakes on. She was so deep into a coughing spell and already on 10l/min oxygen, washing out her blood CO2, while also taking away her drive to breath. Take away too much of her respiratory drive and you will have to intubate her, a mistake to be avoided, one which I had been warned of, so many times over the past years. It was hammered into my brain.

I thought hard for an alternative medication but, standing there, I was so drawn by the urgency to help her breathe that I could not simultaneously concentrate on thinking about physiology. What she had been given the last times, I wondered. With haste, I returned to the nursing station, sifted through the old logs and saw that she had been given morphine, last time, but that she had also nearly stopped breathing. "Doses only 1/3 of normal." Possibly not enough?

With the attending-physician on the line, I scribbled notes as he dictated: Give cortisone 30 mg i. v. first. Then micro-dose 0.5 mg morphine, watch the result, give another 0.5 mg etc. As I turned, the nurse who had awakened me asked the second night-nurse to prepare the medication; she did not want to leave the patient alone any longer. The second nurse rushed for the medication cabinet, visibly in a hurrying, accidentally, dropping the first morphine bottle. They want you to speed up, I thought.

When I got the medication tray to the patient, she was in visible distress. The nurse injected the cortisone, I, the morphine, and we waited for a reaction. A few minutes later, the patient removed her CPAP mask, continuing with nasal oxygen, still coughing from time-to-time. She requested more medication and shortly thereafter the second dose; she relaxed and started to breathe regularly.

As told by my attending-doctor, I could then auscultate her lungs for possible pneumothorax, a lung collapse, which this patient had had before and which can cause a cough, too. While, a few minutes prior, it had been impossible to discern anything through the coughing and ventilator sound, respiratory sound was, alas, audible and equal on both sides.

My attending doctor then called, again, to inquire whether everything was ok, explaining at length that morphine was the most potent medication and that cortisone was a potent medication to suppress coughing. He had learned to use these while working in the intensive-care unit. He said that I had had quite a rough night; something I could not fully judge, then.

The next morning, during a quick pre-morning round where I checked on the patients who had required assistance during the night, before my day-shift hand-over, the patient with the bad coughing attack thanked me. I said I was thankful for having been able to help. Sitting down later to log my shift, I wondered how this situation had come about and why she had thanked me when it had clearly been more than I supporting through the night.

Mobilising and coordinating the distributed elements of the community of practice

Clearly, the events of that night did not represent medical decision-making as a singular cognitive event. Nor did it rely on a single individual's decisions. Instead, it required the mobilization and coordination of those present and elements of the CoP distributed over regions, time zones and sundry individuals.

Drawing on the nurse's experience that the situation would possibly get out-of-hand, the physician had gotten up, adapted his work speed and followed her lead on plausible medication. Then, he contemplated chart entries about a prior adverse medicinal reaction from that specific patient and adjusted the dose in keeping with the attending doctor's experience from prior cases. The attending doctor suggested alternative medication, cortisone, which he had learned to use, in similar cases, in a different intensive care unit. After the patient had calmed down and the resident-doctor had auscultated her lungs, he was able to discern crackles on both sides, relating what he had heard on the auscultation the evening before his night shift started, not to mention those in the hundreds of lungs that he had auscultated on patients, prior. While that excluded a pneumothorax, it would have required an emergency x-ray to be certain of convincing others of the findings. Specifically, that last bit of knowledge is embodied in a way, which was only opaquely encapsulated by the logged words "hoarse crackles over both sides of the thorax."

The written account lacked certainty and social, material and emotional relevance. An x-ray, though, can circulate, as it is founded on centuries of trust that the scientific community has invested into evolving trust in what we see (SCHLICH 1995, DUMIT 2004).

Over the subsequent months, during night shift handovers, whenever colleagues asked about emergencies and their management, I drew on this and similar situation. While talking them through the management of incessant coughing or coughing up blood, or dropping oxygen saturations, it seemed like I was, again, standing next to the patient whom I had had to manage, remembering the ventilators hissing and my swirling emotions. Though unable to transfer this embodied and tacit knowledge, I was aided in prioritizing subsequent situations. My colleagues drew on the explicit knowledge, which I, typically, reduced to two or three sentences, sometimes consulting my night-log into which I had scribbled that night's notes. Sometimes, they are explicitly referred to the guidelines of the standard operation procedures, a formalised version of such notes but a similar knowledge protocol, nonetheless.

This field note excerpt emphasizes the temporal component of the situated learning process. The task of coordination is about spatial distribution over charts, guidelines and different people, but it also shows a temporal distribution. Experience, which is what was gained, is mostly referenced as a cognitive and personal "thing," which one possesses. Here, the interactive and materialized dimensions of *having an experience* (DEWEY 1939),[3] and what Medical Anthropologists GABBAY & LE MAY (2004) call the collective construction of medical *mind-lines*, are foregrounded. This pragmatist take on experience allows us to talk about learning and passing on experience, differently, as explicit knowledge. Rather than making notes of inadequate things, knowing there is "more to it" than can be verbalized or written down, the conditions for re-enacting this distributed-agency and expertise in moments of crisis have been created.

This is the essence of our ecological argument: taking experience and learning out of the individual's head and making it a procedure to be enacted in similar moments of crisis. The embodied memories of myriads of similar crisis situations create a collectively embodied-memory culture on the ward. This culture spawns the atmosphere which patients, like Mrs. Monk, describe as "feeling at home". It also guides the novice while navigating the decision-making on the ward; thusly, helping to make new experiences. The embodied-knowledge of prior generations, that of the attending-doctor, is not passed on but re-generated within the contexts of novices' interactions within the social and material environment. To borrow a phrase from anthropologist HARRIS (2005: 198), the collective experience of the CoP acted like "a wave which carries forward the history of past actions and embodies their potential".

Discussion

In this paper, we described a CoP evolving through a rapid demographic transition that led from a hospital, at the periphery of town, where CF care was secondary, to an existential disease which held a central position in the university expansion and high-tech intervention, like organ transplantations and intracellular protein modification, mirroring a global trend towards an increasing focus on biomedicine and technology in health care. This transition happened at the same time as a shift in health and illness perspectives with the re-conceptualization of patients, as active partners in health care, has taken place in general medicine and CF care.

In our first empirical example we presented the story of one of the oldest patients with CF. We described the specific CoP, the clinical setting in which CF is treated, the development of the CF Centre and the exemplary trajectory of the patient herself. We then turned to the specificities of living and working with CF: How, during the acute treatment in the hospital, a specific knowing practice-collective is performed during morning rounds, the challenges that patients are confronted with outside the hospital during life at work, and the experience of difference based on bodily restraints and visibility of the treatment; but also, how an ironic re-definition of the dominant narratives of CF becomes possible.

In our second empirical example, we focused on the learning processes of the clinical actors. We showed how, in order to respond to emergencies, they have to draw on diverse actors and knowledge formats, without marginalizing the position of the patients. Learning to manage CF was taken out of the head of individual actors and translated into distributed learning processes, including patient and physician, nurse and chart, mechanical respirators and medications, phones and other doctors. We suggested that learning within the community of practice becomes temporalized and, concurrently, experience becomes situated and materialised.

The paper aims to show how *developing an identity* as *a member of the CF CoP and becoming knowledgeably skilful in mastering the challenges of life and work with CF are part of the same process*. We have argued that three interrelated elements are crucial to this, each of which will be discuss in turn:

First, in the development of a shared identity around the question *how to manage and live* with a rare chronic illness, CoP members use irony to establish a position both outside the dominant mainstream of medicine and outside the dichotomies healthy/ill.

As PWCF are getting older, they face new life and health-care challenges. The challenges in filling expectations are more than therapeutic complexity, which, single-handedly, poses a huge burden (Badlan 2006). The possibility for a normal life, created through therapeutic options, may turn into a mandate to live a normal life at the expense of health and life itself (Maynard 2006). Freedom to choose may mean choosing continued existence over long-term survival. Embedded within this set of impossible choices is the problem of integrating oneself, an entirely medicalized life-form (Rose 2007), in a world populated by people who do not thoroughly comprehend the implications of living life with a chronic condition (Vickers 1997). Irony, we argue, is a form of dealing with this. Its use reinstates membership within the CF community and creates a position outside the hegemonic dichotomies of healthy vs. ill. The CF position "outside" motivates, shapes, and gives meaning to the development of the skills, which it subsumes.

Second, managing CF requires mobilising and coordinating the CoP's distributed elements and collective learning in the domains of everyday life and clinical decision-making, cutting across established status groups of patients and caregivers.

The development of the practical knowledge and skills required to care or, to borrow from De Certeau (1988), the artful undertaking of inventing everyday life, with a chronic illness, places PWCF and their care-givers in a pioneering situation; few, if any, were in these situations before and have a big experience advantage (Davis 2006). To complicate matters, knowledge exchange among PWCF may be limited, by their vantage of not being among the sick, on the one hand, and the need to keep them isolated to avoid transmission of the strands of bacteria, which reside in their lungs (Boucher 2008). On the side of care-givers, the specialisation of modern medicine creates heterogeneous geographical and relational spaces that differ from apprenticeships, where identity arises as part of participating in a particular craft or social group. It has been argued recently that in CoP of acute medicine like in emergency departments, patients, nurses and doctors do not share with each other their practice knowledge due to the pedagogic arrangements that are disciplinary based (MANIDIS & SCHEERES 2013). As we have shown for the CF CoP, learning in a setting of chronic illness does cut across disciplines. Not in a formal sense, for we have witnessed no formal arrangements that facilitates doctors learning from nurses or patients, or vice versa. Rather learning occurs as an interstitial practice (LAVE 1991) embedded into activities of decision making as during the night shift. One of the reasons for this difference may be that the pedagogic arrangements and attachments or, as SCHATZKI would name them, the *teleo-affective structures* (SCHATZKI 2006: 1864) in chronic illnesses are not primarily related to the discipline, as in acute medicine, but *through the development of a shared identity,* they are related to the condition and the care of patients.

Third, by taking experience and learning out of the individual's head and making it a procedure to be enacted in similar moments, the embodied knowledge of prior generations of patients and staff is not passed on but regenerated within the contexts of novices' interactions within the social and material environment.

WEBER (1904) famously argued that situations of crisis call for charismatic leadership. His notion of charisma is not a property inherent in the charismatic figure, but considers it an interactive effect, with the group projecting its expectations, and the leader in turn responding to them. In a similar argument, LÉVI-STRAUSS (1963), in his classic "The Sorcerer and his Magic," described how healers evolve to manage situations, which they had not anticipated, through the expectations and actions of a group, which works as a constant field of gravitation in which healer and patients act. Accordingly, the expectation of swift and confident engagement during the night shift and *to care* was spawned by the nurse's expectation, the attending-doctor and the patient. The caring is done *because it is there to be done,* as KLEINMAN (2009) describes this gravitational field in his "Odyssey of becoming more human by caregiving".

A question arising from our research is what counts as evidence of *good care* (MOL 2008), or best practice, when the experience, required to care is elevated to a distributed knowledge practice. It has been argued that good care in practice is never a fixed, and cannot be judged from the outside. Rather, it is a creative process of attentive experimentation, something to do in practice as care goes on (MOL, MOSER & POLS 2010: 13). If we may not say what good care in general is, then, maybe we may say what the conditions for good care are. As a first tentative answer then, by foregrounding the process of *becoming member of a CoP organized around care,* we have illustrated that making experiences that enable healers to be careful and response-able is a dual process that includes being responsive to the expectations of the CoP and care-ful guidance by those that have made similar experiences. Temporising experience points is a second answer of what good care is: A practice not contained in the present but also assuring the possibility of its regeneration in the future.

Together, the three elements—using irony to narratively create an identity "outside", distributed decision-making and temporalizing learning to care across disciplinary boundaries—create a collectively embodied memory culture allowing the CoP to regenerate itself and to adapt within times of rapid change. This underlines the strength of the concepts of situated learning and CoP in helping to conceptualize the question how newcomers are socialized and learn "to be" (LAVE 2008), and thus allow the social reproduction of a highly specialized organization within medicine.

Beyond anthropological interest in the reproduction of social order (SCHATZKI 2001, 2006), our approach also highlights a possible role for anthropological inquiry within the ecology of care. The enduring success of the ecological concept, its "variation" and "evolution" (LEE 2001, GREEN *et al.* 2001, FRYER *et al.* 2003) may partly be explained by the resonance of these metaphors, all borrowed from biology, with biomedical practitioners' thinking. Since its initial conception, the idea of ecology of medical care has been advocated for use in research and teaching directed at improved understanding of the ways of favorably modifying it, with the objective of “reducing the time lag between advances in the laboratory and measurable improvement in the health of a society’s members”(1961: 204). Here, we started from the question, widely ignored in the dominant research on medical care, how medical practitioners’ and patients’ acting in the world builds up a reflective experience (ROLFE 1997) that is consecutively transformed into expertise (BECK 2015), and how this is continually reproduced within a highly specialised ecology of care in times of rapid change. By this, we aim to productively intervene in the dominant research agendas on medical care. Our attempt is positioned among a growing body of research on expert cultures, that have recently moved from studying “the other” to investigating “mutually interested concerns and projects” where “the basic trope of fieldwork shifts from apprenticeship to collaboration” (MARCUS 2008: 7). While we are deeply sympathetic to such a collaborative research endeavour, we would like to revive the idea of “apprenticeship”, albeit in a reflexive perspective.

In an editorial on “Friendship and Fieldwork”, VAN DER GEEST (2015) argues that one can learn far more interesting things, ethnographically, by delving more into a subject than if one confines oneself to an outsider position. We are, now, following this suggestion and including auto-ethnographic elements in our analysis. While the role of auto-ethnography in anthropology is a highly debated one, with critical voices concentrating on methodology, and proponents focusing on the intended effect (ELLIS, ADAMS & BOCHNER 2010), the CoP implicitly suggested this approach on several occasions. One of the CF centre’s psychologists, in order to help a patient understand her own situation better, gave a patient one of our (unpublished) papers in which, drawing on MOL (2008) we described different logics of exacerbation and care under which CF is performed. Another psychologist explained how, during a seminar for CF patient-trainers, she had used the idea of *mukoviszidieren* which translates as “*doing cystic fibrosis*”, a term again floated by MOL & LAW’s (2004) radical-practice theory which purports illness as not only something you are or have but something that is done. While it is unclear how much traction such anthropologic concepts may gain, both instances are hints that curating concepts in close proximity with practitioner is possible. One condition of possibility is the intensive immersion that comes with long-term research. A second, and certainly lucky, condition is the generous offer to epistemic partnership by the CoP’s practitioners. A third, and possibly temporal, condition is the current state of transition and flux of the CF CoP.

The CoP perspective used in the paper, and the trope of apprenticeship, foreground the important role of experience as a form of knowledge that also needs to be managed and transferred and that must not be considered an individual cognitive phenomenon respectively. While we have demonstrated how decision-making and experience are distributed across team and equipment, reflection seems to be somewhat less subject of distribution at a first glance. Following BOYER’s (2015) inquiry how reflexivity is produced within modern epistemic, social and material architectures, one might want to question further where, how, by whom and with what kind of consequences reflexivity is produced within such distributed knowledge practices. Reflexivity in the distributed knowledge practices of CF happened as musings during interactive interviews, informal discussions during coffee breaks and moments of generously available time outside busy daily work as during rounds on weekends. It was present as an interstitial practice, and its effects become visible in the recirculation of anthropological concepts within the CoP mentioned above. This appears very unlike the famously unsuccessful WTO para-site including a staged presentation and explicit reflection (DEEB & MARCUS 2011). Possibly, formally staged events outside the field are just as lousy places for anthropological reflexivity, as formal schooling settings are lousy places to learn anything in, to paraphrase BECKER (1972). The analogy may be controversial, and we do not dismiss the value of the para-site experiments. Yet our intention is to foreground the already happening reflexivity-in-the-field and the possibility to connect and participate in reflexivity-in-practice, which we believe to be a widely distributed and ubiquitous feature of contemporary science and medicine (BECK 2008).

We believe that these further inquiries would benefit from not only writing about, but also becoming part of the practices at the intersection between the theory and practice (INGOLD 2013). Anthropology as a discipline will have little to add to the practitioners' point of view in modern medicine's already highly reflexive communities, unless it engages in joint epistemic work with its research partners by irritating established thought styles and collectives and curating concepts jointly (NIEWÖHNER *et al.* 2016). Within such a co-laborative research agenda, auto-ethnography appears a useful methodological entry point because it allows us to *study sideways* (BOYER & HANNERZ 2006) when reflecting on good care, the production of a skilled identity and the reproduction of a community *from the inside*.

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Notes

1 While RISOR, himself a physician studying younger colleagues, is the exception, he points out that he refrained to actively counsel his informants unless they first laid out their course of action if he wasn't present. It would of course have been unethical had he withheld knowledge during emergencies.

2 Transplantation is one possible treatment for terminal CF but it is risky because the lungs are highly immunogenic organs, the consequence of its large surface to the outside world, accordingly exposing a high risk for rejection. Of the 25 patients who were part of the initial study-sample, ten years ago, three were successfully transplanted while three others died shortly after transplantation rejection or transplant failure. The question, whether to take transplant risk is not only a medical one but deeply embedded in the social norms of our ablest society (MAYNARD 2006).

3 DEWEY distinguishes between *experience* and *an experience*. While experience occurs continuously in interactions of living beings and environing conditions, having *an experience* by humans is characterized by the unity of emotional, practical and intellectual dimensions of the situations or events such perceived (DEWEY 1934: 39). See also BECK (2015) for a discussion of Dewey's pragmatist approach for a practice-oriented take on ecologies of expertise.

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