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WHEN CARE STRIKES BACK – SOME STRATEGIES AND TACTICS FOR DEALING WITH AMBIVALENCE OF VISIBILITY IN CHRONIC ILLNESS

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Abstract: Building on the works of sociologists of health and illness that have highlighted the effects of visible difference and stigmatisation since Goffman, this article examines the ambivalence of visibility experienced by people with cystic fibrosis (CF), a fatal chronic disease and the artful tactics they employ in carving out a habitable space in an ableist world. Dealing with the ambivalence of being at once inherently ill and apparently healthy is a process of giving constant care and attention to one's body and its presence in public, and if successful, enabling those affected by it to acquire a new - albeit temporary - healthy self with the help of therapy.

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Introduction

Anthropologists have directed our attention to the struggles of marginalized individuals and groups like those with a chronic illnesses to gain greater public visibility of their therapeutic burden. Yet, only modest attention has been paid to the efforts put into achieving a visible normality through therapeutic practices or to the therapeutic work behind this apparent normality (Robbins 2013; Ortner 2016).

We present here the results of a longterm anthropological study in collaboration with a group of adolescents and young adults who have cystic fibrosis, a fatal genetic condition. Through fieldwork in Berlin, Germany, we explored how young people – who often do not readily appear to be sick – integrate therapy into their daily lives (Jorgenson 1989).

Building on the works of sociologists of health and illness that have highlighted the effects of visible difference and stigmatisation (Goffman 1969; Yang, Kleinman, Link et al. 2006), this article examines the ambivalence of visibility experienced by people with CF. We extend the conceptual framework put forward by Michel de Certeau (1980) in his studies of the practices of everyday life of marginalized people to those living with a chronic illness to show the artful tactics they employ in carving out a habitable space in an ableist world.

We follow the story of a group of young people we met in 2007 at an outpatient clinic,

and re-encountered several times over the last 10 years. As both anthropologists and doctors, we are interested in their struggle for well-being, care and with morality (Mijazaki 2004).

Living with CF

It was a warm summer day in Berlin. Tanja (a pseudonym) and I met at a photography exhibit in the city centre. She was one of the young adults with Cystic Fibrosis we followed in the course of our research. At the entrance to the exhibit, Tanja flashed her disability card and asked for free entry for herself and one of us as her “accompanying person”. The young man at the desk looked at Tanja with hesitation, his eyes moving between Tanja and the card she held in her hand. He seemed to be assessing whether Tanja was attempting to elicit a benefit to which she was not entitled. Tanja was an good-looking young woman in her early twenties. She spoke quickly and confidently in a way that troubles categorizations like healthy/ill, able/disabled, and the tendency to equate illness and unattractiveness (Hall 1997). Tanja didn't fit the stereotypical image of a disabled person who requires someone to accompany her. By using the card, she transgressed forms and expectations, rendering her in some ways un-intelligible and difficult to “sort out” (Bowker & Star 1999). This un-intelligibility is a part of the burden of living each day as a young person with a fatal chronic illness (Badlan 2006; Williams et al. 2009)

CF is a rare genetic disease that causes frequent respiratory infections, leading to progressive scarring of the lung tissue. Most people with CF will start their therapy in the first years of life and will require a lung transplant at some point in their lives; those who do not receive a transplant often die from suffocation. There is currently no cure for CF, but its progression can be slowed (Ratjen & Döring, 2003). In Europe and North America, the life expectancy of someone with CF is approximately 38 years and it has been continuously rising in the last decades from around 15 years in the 1960. Responsible for this increasing survival is not a single new drug, but a more complex and demanding therapeutic regimen (Davis 2006; CFF 2009). It involves approximately 2 hours of inhalation and chest physiotherapy every day, and up to 7 different oral medications (Sawicki et al. 2009). Patients consider this therapeutic regime as burdensome and time consuming, and treatment is seen as marker of illness and stigmatising (Bregnballe 2011). Especially for adolescents and young adults it is a continuous challenge to integrate the therapeutic regimen into daily life with school or work, family, friends, and leisure activities (Staab et al 1998). Faced with the possibility to be part of their peers, young people with CF employ an arsenal of tactics to hide the work behind their normal apparence (Ernst, Johnson & Stark 2010).

Adherence to the therapeutic regimes is around 50% (Llorente et al 2008). While poor adherence to this complex therapy is recognised as the main cause of treatment failure and increased exacerbation rates (Eakin et al 2011), some authors suggest that educated non-adherence with a treatment may be an adaptive way of coping (Dodd & Webb 2000). Since nobody is able to be 100% compliant with long-term treatments, it seems reasonable to aim at 'educated non compliance', so the patient is capable to decide together with the CF team what is important for him and what could be skipped for a certain time. Patients and caregivers are balancing out which minimal therapy works for them at a certain moment (Havermans & de Boeck 2007).

When care strikes back at normality

The balancing act takes on particular significance if a therapeutic regime is very successful. As one physician told us during an interview:

> *There may be moments when doing more therapy leads to better health, and at this point you reduce therapy – because everything goes well. Some patients are then able to lead a life undisturbed by therapy for a period of time. In such a moment of relative stable health even very little therapy can be very disruptive.*

In the last case referred to by the physician, the effect of increased therapy levels off and reaches a plateau. Economists would say from a certain point onwards, extra treatment has decreasing marginal utility. Patients whose health-state demands for a treatment burden beyond this plateau experience a double bind, like one of Tanya's friends:

> *When I was still at primary school, some teachers sent me home when I was coughing, saying "come back when you are healthy". But I would still be ill in a week! So, I realised that I didn't have to cough as much if I didn't inhale in the morning. Smart, aren't I?*

The dynamic described by Tanja's friend is experienced by many other patients as 'normality striking back at therapy'. To appear normal in a period of relatively stable health, therapy has to be absent. Although the young patient did her inhalation at home, she was still ill to her peers and teachers when she coughed in school. As coughing made her illness apparent, the therapy didn't work at that moment. Even if it would lead to better health in the long term, the adverse effect of inhalation therapy made illness visible. When more treatment leads to more symptoms, while less treatment leads to greater chances to spend time on activities with peers, skipping therapy seemed a rational choice.

People in such a situation will generally want their condition to be invisible to the public. As they are at constant risk of outing themselves involuntarily, they have developed an arsenal of strategies for passing (Goffman 1963). Through therapy, they can render their illness invisible to the general public. Their illness is of course perceptible to themselves and to their doctors, and perhaps other patients. Some subtle signs like clubbing of the fingers that indicates lack of oxygen, a hump in the back that hints to overinflation of the lungs, a hoarse voice from inhaling and the salty taste when you kiss someone with CF will be put together by people that Goffman (1969) called "the wise" - those that know the sings of an affliction by acquaintance.

The difficulties related by the to "sort out" Tanja at the exhibition, or her friend at school reveals their double status as someone who is at once ill and apparently healthy (Bowker & Star 1999), but also the possibility to manage this double status by tactically revealing either status.

CF therapy has traditionally taken place in hospitals. But, increasingly, the space of therapy is becoming fluid. With the help of procedures like inhalation, chest physiotherapy and the delivery of intravenous (IV) antibiotics, patients have gained opportunities. For this to occur, certain technical innovations were essential – such as replacing the standard and somewhat clumsy hospital infusion pump with a smaller one. Patients can slip this smaller pump into a trouser pocket, running the IV line under their shirtsleeve. Moving therapy out of the hospital means greater freedom for patients living with CF, but it also means that they have to integrate therapy into the practices of everyday life, particularly at home.

Strategies and Tactics for managing the visibility of illness and therapy

We follow here Michel de Certeau who differentiated tactics from strategies. Strategies are calculation of power relations that require a place, a basis for organising relations, while tactics cannot calculate with a won space, but have to use the space of the other, and cannot capitalise gains. A hospital or a research laboratory would be such places where doctors and patients can strategically develop and test therapies, devices or drugs. Outside a hospital, patients are only able to deploy their tactics at a “right moment” in order to control illness and it's visibility. Since tactics cannot be planed in advance, they require experience to recognise and capture the “right moment”. While strategies are dependent on the use of a place, tactics are dependent on the use of time (de Certeau 1980:23).

One frequently employed tactic is to disclose illness only to certain people. Knowledge about CF would be shared with close friends only and only rarely to casual encounters – like Tanja at the museum.(Borschuk et al. 2016). Differential disclosure is employed to mitigate negative repercussions or negative consequences when disclosing to romantic partners and in the workplace (Modi et al. 2010) As Tanja explained „Emotions are quite strong, I've been able to suppress the urge to cough for a really long time, when I came home at night with someone I didn't want to know of my CF.” While it is assumed that greater disclosure is associated with higher disease severity (Lowton 2004), here, we attempt a more fine grained analysis. Almost all patients we have worked with oscillate in their relation to CF. *'Being normal'* and *'doing therapy'* are modularised in space and time so as to manage their therapy in a way that CF does not reappear in public. While it is not possible to observe that in casual or clinical settings, participant observation at patients homes provided insights into how patients manage this. The remainder of this article is illustrating that way of coping.

In Tanja's apartment, a handful of pills lay on the kitchen table. I recognized them as the pancreatic enzymes many young people with CF have to take with every meal so that they can absorb nutrients. On a nearby shelf, there were boxes of vitamins, anti-inflammatory drugs and antibiotics. Another box of antibiotics sat next to the cheese in the fridge. Beside a bookshelf was Tanja’s nebulizer, a handheld device the size of a small bottle. Through a mouthpiece on it's top, Tanja inhales hypertonic saline for up to 30 minutes, two sessions per day in order to dilute the mucus that builds up in her lungs.

On one of the many occasions when Tanja’s physiotherapist visited, talking was also part of the session. The two of them began by catching up on the latest news and events: patients who had gotten better lately or taken a turn for the worse, and their holiday plans. Only after socializing did Tanja lie down on the couch to begin chest-physiotherapy, a procedure that involves chest compression and decompression to mobilizes the mucus in the lungs that can then be coughed up slowly (image 2). During the treatment, Tanja’s face became red and the room was silent except for her repeated coughing. These moments of coughing were a stark contrast to the casual social encounter that began the 30 minute long session; suddenly, Tanja’s illness was starkly present. But, after one seemingly endless minute of exertion, Tanja spat the mucus into a small sealable container and the chatting continued.

As in during the physiotherapy session, there is a constant blurring of lines between therapy and everyday life for young people living with CF today. Tanja and others described to me how the dramatic intensity of

life with CF can lead to close relationships. Many patients have relationships with other patients, and sometimes marry. Patients and medical staff like to go to exhibitions and concerts or on vacations together. One doctor remembered being called on the phone in the middle of the night by a patient who had gotten lost on the highway while hitchhiking. Although initially patients like to keep distance between the hospital world and day to day life, with time they become increasingly entangled.

But the value of participant observation based research are close relationsships and a becomming with participants (Ingold 2013). At the beginning of this project, I was warned by the staff at the CF clinic that they have seen several of their younger doctors become emotionally attached to patients who later died. During the first year of research, three of the 15 patients I followed passed away and several have since during attempted lung-transplantation or while waiting for one. But the close relationships that were formed with some of the young adults we followed were fundamental to our anthropological work – and in some ways difficult to avoid in a research envisioned as a collaborative process. We were similar in age and interests to many of our collaborators; they, in turn, were often enthusiastic about reflecting on the ambivalence of their visibility in the context of our work together.

That same night when her physiotherapist had visited, Tanja came out of her room before bed to put a gastric tube through her nose. She connected it to a bag of high-caloric food to ingest into her stomach while she sleeps. These extra calories are essential to meeting the increased energy demands experienced by people with CF, who experience a constant inflammation as a result of fighting chronic respiratory infections and generally have to work harder to breath. The gastric tube is not a comfortable procedure; in fact, Tanja knows of only few other people who do it. “I also usually do not show this to anyone,” she laughs. Doing but not showing is what allows her to be normal most of the time. While spending time with patients, it was sometimes hard to notice them doing any therapy at all over a day. Some strategies resemble technical fixes, like having a port inserted instead of an i.v. access or taking cortisone before going to nightclubs, where cigarette smoke could trigger a bronchial hyperreagibility and lead to the constriction of the airways.

Some of the tactics they employ are quick cover-ups, like stuffing pills directly into a sandwich instead of taking them with liquids during a meal. Other tactics resemble Mimikri, for example using explanations like „It's sth. like Asthma“, a trope frequently employed by several of our collaborators when they were asked why they coughed instead of explaining CF. During those times when she needs IV antibiotics, Tanja would make the cotton covering the IV line on her forearm a little thicker, transforming it into a “sweat band” so that the line wouldn't be as visible. One day, she and a friend were asked about those „sweat bands“, while at a hairdresser who remarked that they had an iv line underneath them. Tanjas friend told us the hairdresser had inquired if they were taking methadone because they looked so pale. She sighed, stating that being taken for one who is on a drug replacement programm which is clearly stigmatizing was still better then explaining CF to a casual encounter. Table 1 lists some strategies and tactics we found.

Some challenges can be fixed using clever tactics, some by medical progress and some cannot be fixed at all. For some situations, like the direct transfer of oxygen to the lungs, which some patients require, such quick cover-ups and mimicries cannot be applied. Inhalations need time to prepare and to be

carried out. To clear the mucus, mobilised by inhaling, one needs to cough afterwards, because of the urge to do so caused by inhaling and because without coughing the mucus out, inhaling is considered medically useless.

The strategies and tactics work out quite well most of the time, but they are precarious, and can fail at exactly the wrong moment, as we will see in the next section.

Table 1. Strategies and Tactics for managing the visibility of illness and therapy

Strategies	**Example**
Technical fixes	Smaller infusion pumps, port systems, gene-repair drugs (ivacaftor)
Tactics	
Non-adherence	Inhaling less in order to avoid prolonged coughing in public.
Differential disclosure	Using different levels of involvement and disclosure, like telling romantic partners and friends but not your boss.
Oscillation	Switching between relating to CF as therapy being normal
Mimicry	Using explanations like „It's sth. like Asthma“, accepting being taken as on a drug replacement program instead of explaining CF iv-therapy.

When tactics fail: dealing with the ambivalence

What enables patients to participate in an apparently normal way is a permanent gestalt-switch between relating to CF as 'therapy' or being normal. Problems with this arise when an element causes a gestalt-switch at a wrong moment: One day a friend of Tanja who was studying medicine slipped away at the break during a seminar at the hospital to get an i.v. line for her home antibiotic therapy. The old i.v. was clogged and she needed a new one quickly in order to get back to her seminar before it started again, so no-one would ask questions. To repair it she had to improvise a 'hospital setting'. She went to get a new i.v. line on the ward and found someone to put it in place. But doing this during a short seminar break, time is of the essence. Placing a i.v. in a CF patient often requires patience. The aggressive antibiotics used to combat infection make it more difficult to find a good vein after each therapy round. At that very moment, no doctor had time. So another patient, who was also a doctor was recruited for the procedure. Straight afterwards, the moment she slides the infusion pump into her pocket, she is back to normal. It seems as if she is carrying the hospital in her pocket.

This requires a lot of work, and it is risky. If it becomes apparent that one has an infusion pump in the pocket, all the skilful work of

concealing will be futile. The desire to appear normal is so strong, that there are moments where patients would rather run the risk of seriously deteriorating their health than to disclose being ill through doing therapy.

The next morning, after Tanja used her inhalation machine for half an hour while reading a book, we drove by the office were she had worked until recently. She recalled, "At work I had to justify myself whenever I was late – that I just did my inhalations and wasn't lazy. It's difficult to explain every time – even some people who work with you don't seem to understand." Tanja remembered a colleague who had told her about how one of his acquaintances had gotten a renal transplant, and how horrible that idea was to him. "I was struck with disbelief", Tanja said, shaking her head. "I told him I might need a lung transplant in the not so distant future. He didn't get it – perhaps I still look too good?"

The more therapy young people like Tanja do, the better they look. But the better they look, the higher people's expectations are regarding their level of functioning. As one of Tanja's friends, who is still working, told me during an interview:

> *I consider doing my therapy, in the way that it now fits into my life, as a disadvantage, because you don't belong to any group. You are not part of the ill ones…but neither are you part of the healthy ones. That makes it difficult, because you have to justify yourself whenever you try to integrate yourself [into either group]. You are not part of any group, and you have to excuse yourself for what you don't have – illness or health.*

Immigrants to health

As Kaufman (2010) has argued, in cases of serious and chronic illness, clinical practices contain the challenges for those who are ill to imagine certain kinds of futures in which one's corporeality is central, and to choose among medical options in order to move toward one kind of future instead of others. The logic that places the needs of acute everyday life above long-term survival is deeply embedded in the social practices of an ableist society (Maynard 2006). Patients with a chronic condition do not want to survive, they want to live. Living with CF means dealing with ambivalence of visibility since, while visibility of illness excludes them from the group of the healthy ones, it is also a resource that can be used to gain support and care. Yet, this ambivalence can only be navigated purposefully to a certain extent. To many out-standers, the double status of someone with CF – who is at once inherently ill and apparently healthy – is un-intelligibility. Most will try to sort them into either group.

The German philosopher Hans-Georg Gadamer (1993:171) romantically said that health is equal to a "self-forgotten state of abandonment to the future". Kathy Charmaz (1981) once argued the experience of chronic illness to be a loss of self. As this paper has tried to show, those with a chronic condition like CF, who have 'never not had it' cannot be said to experience a loss of a healthy self (Williams 2009). Neither are they self forgotten. Being alive for them is a state of constant attention to their self and its presence in public, rehearsing their arsenal of tactics of disclosure and mimicry and oscillating between being normal and doing therapy.

This constant oscillation between normality and therapy is line with an argument by Joseph Dumit (2002) who observes that since the 1990s the paradigm of "inherent health" and illness as deviation from the norm has been replaced by a notion of illness in which bodies are inherently ill and a precarious self arises that needs constant maintenance to keep symptoms at acceptable levels. Dumit

proposes that through the treatment of a chronic disease, a precarious self arises that needs constant maintenance to keep symptoms at acceptable levels. The new 'normality' is thus not a return to the previous set of symptoms, but a 'virtual normality that is dependent upon medication'.

We would like to extend Dumits proposition. With the help of a very complex and demanding therapeutic regimen, people with CF are able to make the symptoms of their illness invisible, thus allowing them to acquire a new – albeit temporary – healthy self. They become 'immigrants to health', to turn around Susan Sontag's (1978) phrase. Acknowledging the burden of therapy they face, and claiming the kinds of social support to which they are entitled as 'disabled' persons, may come with the loss of a sense of belonging in the world of the able bodied. This was a kind of temporary citizenship that many young people deeply desired.

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Notes