Stefan Reinsch:

»Life Expectancies«

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LIFE EXPECTANCIES Surviving Predictions

"My parents were told I wouldn't survive until the age of ten. When I got to the age of ten, I heard doctors say, 'You won't live until eighteen'. When I had beaten that age, and was twenty, then I was told that I wouldn't reach thirty. Now I am heading towards forty [...]. That's how, somehow, I smuggled myself through life until now."

Interview with Ricky (2007).

Ricky grew up in a small town in southern Germany in the 1980s. He was born with cystic fibrosis (CF), a rare, progressive, and ultimately fatal genetic illness affecting many organs. At the time of Ricky's birth, life expectancy for someone with CF was around eighteen years in so-called developed countries.



Photograph by Johannes Rascher (2007).

Ricky during a hospital stay. He is holding a box of pills in his right hand. The shirt's logo states: "Der Sonne entgegen" ("Towards the sun"). On his left arm is the name of the island where he worked as surfing instructor. The images in this essay are part of a photo-ethnography project, in which Johannes, a photographer, and I followed people with CF through their lives. All people agreed to be part of the photo-series, as well as to online and print publication.

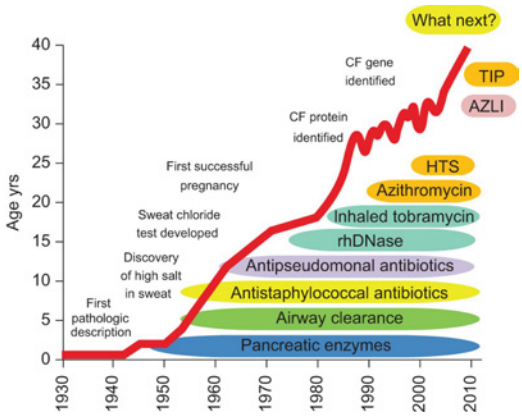
After his CF diagnosis as an infant, his parents abandoned him at an orphanage. His parents' radical rejection of him and his illness arose from an extreme position that several adults with CF, as well as some CF physicians, have related to me. At the time, health professionals sometimes advised caregivers against developing close attachment to a child with such a diagnosis. Speaking about growing up with CF, Ricky told me how he had repeatedly beaten the predicted life expectancy. I met Ricky for the first time in 2007 at a time when he was admitted for two weeks to the hospital ward where I was doing ethnographic research for my dissertation. He was then 36 years old, and the life expectancy for people with CF in Germany had doubled since the year of his birth. I found him to be an athletic and positively minded man. He was working part-time in a hardware store, leaving him the time necessary to do his therapy. At one episode in his early thirties, his health had deteriorated, and Ricky asked his employer for extended leave to work as a surfing instructor on one of the German islands in the North Sea – a place where people with CF go for climate cures. Ricky's creativity impressed me, as inhaling vapours from saline solution and physical exercise are two pillars of therapy for CF. After I graduated to become a physician, I started to work as a paediatrician in a university hospital in eastern Germany to be able to continue research with Ricky and the other young people who have CF.

I wanted to understand his endeavour to live a good life, while being confronted with his mortality, and the wearying threat of a worsening infection that could ultimately be fatal, thus defying repeatedly the odds of survival.

Indeed, Ricky was exceptional at this, and by telling his story, I now attempt to put words to this life with CF – a state that we physicians, and likewise patients living with CF, have found difficult to grasp. The changing demographics over the last decades have placed people with CF in a pioneering situation: few if any have previously enjoyed this position, so there have been scant role models among people with CF, leaving them to improvise their life in the course of living it.

LIFE EXPECTANCIES Cystic Fibrosis Care

CF is a hereditary disease affecting one in 2'500 people in Europe. A multi-organ disease of variable severity, its clinical hallmark is frequent respiratory infections that lead to progressive scarring of the lung tissue. Although currently there is no cure for CF, medical therapies can slow its progression.[1] Despite initiation of treatments in the first years of life, most people with CF will come to require a lung transplant at some point in their lives; those who do not receive a transplant often die from respiratory failure.[2] In Europe and North America, the life expectancy of someone with CF is now approximately fourty years, having continuously risen from about fifteen years in the 1960s. The development of a complex and demanding therapeutic regimen accounts for this substantial increase in life expectancy,[3] notably in including the introduction of basic-defect modulators. Current therapy involves approximately two hours of inhalation and chest physiotherapy every day, and up to seven different oral medications.[4] Despite optimism arising around the new and highly expensive therapies, life expectancy remains several decades less than among peers without CF. Adherence to the onerous therapeutic regimen is reported to be around 50% among CF patients.[5] This poor adherence to the complex, time-consuming therapy is the main cause of treatment failure and clinical exacerbation.[6] However, factors other than the regularity, number, and intensity of therapies can influence clinical progression of CF.[7] Independent factors in progression include gender of patients, their socio-economic status, and the place of treatment.[8]



J. Stuart Elborn: "Personalised Medicine for Cystic Fibrosis: Treating the Basic Defect", in: *Eur Respir Rev* 22 (2013), pp. 3–5. © European Respiratory Society, reproduced with permission.

Demographics with key dates and advances in CF care from the 1930s. Reproduced with permission under the Creative Commons Attribution-Non-commercial 4.0 licence. Original captions: Schematic illustration of how the introduction of novel cystic fibrosis (CF) therapies influenced patient survival over the decades. HTS: high throughput screening; AZLI: aztreonam for inhalation solution; TIP: tobramycin inhalation solution.[9]

LIFE EXPECTANCIES A Full Life

Phenomenologists have argued that the existential dynamic of people with CF is defined by continual biographical revisions in anticipation of their future illness trajectory and life course.[10] The experience of living with CF is like moving on uncertain terrain, pursuing a future that is threatened and continually redefined.[11]

"I want us to stop using the 'Life Expectancy' Statistic. Cystic fibrosis *life expectancy* gets tossed around like any number of statistics in the medical world. It's something that people love to talk about or use to show success and progress. [...] Now, I totally understand why the life expectancy stat is thrown around so loosely. It's used as a fundraising motivator, a sign of medical/scientific success and a notice for what a family can expect in life for a son or daughter who has just been diagnosed with CF. Certainly we use it [...] to show progress, but also why it is so important that we keep the fight going. The bottom line is that we still have a really long way to go, and at the end of the day, cystic fibrosis is still a killer, so it remains *terminal*. The only people that ever talk about it (other than right now) are people who don't have CF. I can tell you that I've never had a conversation with another CF patient and said, 'so what do you plan on doing with your 51 years of life?' [...] My goal in life is not to outlive the life expectancy of CF – I think that sets the bar too low – rather I want to live a full life [...]."

Gunnar Esiason: "I Want Us to Stop Using the 'Life Expectancy' Statistic", https://www.gunnaresiason.com/life-expectancy/ (15 November 2016).

Statement of a young man with CF.

People with CF are born with the condition, so they have never not had CF, and consequently do not know what it is like not to have it.[12] Otherness is part of the burden of living as a young person with a fatal chronic illness.[13] Like in many chronic conditions, belonging to the world of the healthy is something that young people with CF deeply desire.[14] Although mainly an invisible illness, CF can become apparent through frequent exacerbations of chronic respiratory infections, but also via the intrusive daily therapy that prevents exacerbations.[15] When disabling conditions like CF become visible, or what Goffman has called "discredited" or "stigmatized",[16] 'normal' people may react with staring; as a result, social interactions become uncertain and ambiguous, problematic, tense, or even awkward.[17] For people with CF, avoiding unwanted scrutiny or stigmatization, passing as 'normal', and achieving a sense of belonging to the world of the healthy, are therefore conditional on the absence of noticeable symptoms of their illness.



Photograph by Johannes Rascher (2007).

A couple during an admission at the CF ward. One of the partners has CF.

LIFE EXPECTANCIES Shared Doctoring

Often people with CF like Ricky do not at first glance appear to be sick. To outsiders, their illness may become invisible through their therapy, but if they conceal their therapy from others, the therapeutic work that made their illness invisible also becomes absent from the perspective of outsiders. The young people with CF, whom I met in the course of my ethnographic research, fervently aspired towards the attainment of seeming normality. Invisibility

of illness is achievable with the help of the very complex and demanding therapeutic regimen.

"The thing about patients with CF is that they're good scientists. They always experiment. So, they stop doing their treatments. And what happens? They don't get sick. Therefore, they conclude, Dr. Warwick [one of the most eminent CF physicians in the US] is nuts. [...] We must help them interpret what they experience as they experiment."

Atul Gawande: "The Bell Curve: What Happens When Patients Find Out How Good Their Doctors Really Are?", in: *The New Yorker* (6 December 2004).

This therapy allows people living with CF to acquire a new, albeit temporary, 'healthy' self. The absence of symptoms visible to others is, however, not stable, but a liminal state that is revocable at any moment. One reason for this is the complex daily therapeutic regimen which consists of taking pills by the handful, exercising vigorously, and undergoing chest physiotherapy and inhalation therapy. Much of this burdensome and time-consuming therapy occurs at home, thus limiting the time available for 'normal' activities. Besides, patients consider their treatment as a marker of illness and stigmatisation.[18] Acknowledging the 'burden of therapy' they face and claiming the kinds of social support to which they are entitled as 'disabled' people may come with the loss of a sense of belonging in the land of the able bodied.[19] Many young people with CF deeply desire a temporary citizenship of that figurative country. Especially adolescents and young adults with CF contend with a continuous challenge to integrate the therapeutic regimen into their daily life, along with school, work, and engagement with family, friends, and leisure activities.[20]

Aiming to merge seamlessly with the life of their healthier peers, young people with CF employ an arsenal of tactics to hide the strenuous efforts behind their appearance of normalcy.

Considering these ambivalent effects of therapy, and given that nobody can be one hundred percent compliant with long-term treatments, some authors have suggested that educated non-adherence to a treatment may be an adaptive way of coping.[21] Other clinicians have gone a step further, suggesting that a reasonable strategy for clinicians would be to aim towards "educated non-adherence", implying that the patient is capable of deciding, together with the CF team, what is important for him or her and what might be skipped for a certain time. In this pragmatic view, adjusting medication and therapy-related decision-making are joint efforts, whereby a patient with CF and the health care providers arrive at a compromise or optimization about what minimal therapy suffices for the patient at a certain moment to live a good life.[22] The next sections present some collaborative experiments in everyday life with the aim to achieve such a good life. In these experiments, professional knowledge and therapeutic decision-making are linked with patients' tactics and expertise, thus presenting examples of what Mol, Moser and Pols have called "shared doctoring" and "therapeutic tinkering".[23]



Photograph by Johannes Rascher (2007).

A handful of pills along with each meal that become 'absent present' therapy, once swallowed.

LIFE EXPECTANCIES Still Be Ill in a Week

"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?"

Interview with Adriane (2007).

One frequently employed tactic in dealing with chronic illness is to disclose it only to certain people or in certain circumstances.[24] However, the visibility and frequency of CF therapy makes difficult this tactic of passing and covering.[25] As a result, people with CF sometimes abandon their therapy altogether, in hopes of appearing normal in the public sphere. Adriane, a 22-year-old patient with CF and a medical student, reflected upon this decision as a double bind: To appear normal during a period of relatively stable health, she had to neglect her therapy. Although this young patient did her inhalation at home, she still appeared ill to her peers and teachers when she coughed in school. Insofar as coughing made her illness apparent, the therapy was not effective. Even if it led to better health in the long term, inhalation therapy had the adverse effect of making her illness conspicuous.



Photograph by Johannes Rascher (2007).

Physiotherapy session to mobilise mucus.

When more treatment leads to symptoms that are more visible, like increased coughing due to respiratory treatment, while less treatment leads to greater chances to spend time in activities with peers, skipping therapy can seem a rational choice.

This conundrum is not limited to schoolchildren. To compensate for the visibility of treatment, adult CF patients may overemphasize their ability to fulfil social roles and their capacity for autonomous functioning, while at the same time reducing visibility and the burden of therapy.[26] The dilemma of disclosure for people with potentially 'invisible' chronic illness, and the incumbent threats to emotional and physical wellbeing is an issue for many conditions.[27] With CF, visibility is something that is not firmly in the patient's hands, but rather in a precarious state; a time with absence of visible illness is something revocable at any moment by unexpected exacerbations. The medical literature generally attests to how therapy has the potential to make an illness invisible. In CF, however, therapy can have the opposite effect, as with the necessity to cough after inhalation therapy.

LIFE EXPECTANCIES Tinkering with Therapy

"My colleagues told me 'Maja, you really look bad'. Then I called the CF ward and asked to be admitted. This was a semi-social admission; my physician and I were totally clear about it. It was just too much with work and private life at that moment [...] 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 must justify yourself whenever you try to integrate yourself [into either group]. You are not part of any group, and you must excuse yourself for what you don't have – illness or health."

Interview with Maja (2007).

Tinkering with their therapy over extended periods, people living with CF become experts in an emerging "medical form of life"[28] that feeds back into their relations with clinicians and researchers, their body, and with fellow patients. Their garnered experience allows them to recognize hints that their basic therapy is failing, which calls for taking different measures. One tactic is to seek admission to the CF ward, which extracts them from the public space and into the protected space of the hospital. Another tactic is fitting even more therapy into their life. A discussion about the respective merits of both tactics evolved on the CF ward when, during an interview with Maja, a 32-year-old physician who herself has CF, a younger patient with CF, Adriane, entered the room. Maja had just related how she had continued working, ignoring her worsening health state resulting in worsening of her chronic respiratory infection, called acute exacerbation. When her colleagues gently prevailed upon Maja to take a sick leave, she organised with her physician a two-week admission to the CF ward for a course of intravenous (IV) antibiotics.



Photograph by Johannes Rascher (2007).

Frequent courses of aggressive antibiotics lead to scarring of accessible veins. This makes placing an IV access a procedure that requires skill and time. Some patients would know where to find a good vein that was not visible, and a physician who was not skilled in the eyes of the patient would not be allowed to 'try' puncturing this vein. The physician shown in the image was called upon in such a situation. Before the image was taken, he had asked the patient to warm his arms under running water for five minutes to dilate the veins and make them more visible. In addition, he was using a yellow needle that is comparatively small and flexible, making it easier to access small veins, but more difficult to puncture the scarred veins in CF patients.

Adriane was in a similar situation of a worsening infection. While her physician thought Adriane should enter hospital for a course of IV antibiotics, Adriane herself was reluctant to suspend her daily life for several weeks. She wanted to continue attending her classes at medical school and go on an excursion. Her physician and she settled on a home IV course that would allow her to participate in daily life, with the only restriction of carrying an IV line under her shirtsleeve, which she had to connect to a self-compressing container carried in her trouser pocket. This technical fix became problematic as the aggressive antibiotics used in CF led to clogging of Adriane's veins, a frequently occurring difficulty. During the interview with Maja, Adriane entered the room and asked if Maja, whom she knew to be a physician highly skilled in the procedure, would be able to place a new IV access. Adriane explained she was having trouble finding an on-duty physician at that time. She needed to start her next cycle of IV therapy while in between two classes, which made it difficult to wait until a physician on the ward became available. Adriane did not have time for this now. She had already assembled all the necessary materials, so Maja had only to place the needle. This ordinarily simple procedure required more skill than on a regular patient though, as many superficial and easy-to-puncture veins will have scars from the repeated antibiotics courses. As a result, it often takes several minutes to locate and puncture a suitable vein, even in young patients.

Recruiting a fellow patient to help her out seemed somewhat on the fringes, but this expedience shows how the situational and embodied knowledge of the two patients interacted.

This helped formulate a tactic to replace the blocked IV line without attracting undue attention. The aspiration was that none of Adriane's fellow students should notice she was on an IV course or ask questions concerning her prolonged absence, so that she could continue fitting therapy into her life. The situation that young people like Maja and Adriane faced seemed like a double bind: The more therapy they did, the better they looked to others, but the better they looked, and the more their illness and need for assistance became inconspicuous, the higher were people's expectations regarding their level of functioning. Years of experiencing this double bind led Maja to see fitting therapy into her life as a disadvantage.

LIFE EXPECTANCIES Immigrants to Health

"Illness is the night-side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick."

Susan Sontag: *Illness as Metaphor*, New York: Farrar, Straus and Giroux (1978), p. 1.

Invisibility of illness leads to heightened expectations from others regarding the patient's social functioning, and not belonging to what might be called the "kingdom of the ill", as famously described by Susan Sontag in her book, *Illness as Metaphor.*[29] The double status of someone with CF – at once inherently ill and sometimes appearing healthy – results in unintelligibility of the patient as a person with a chronic illness, as most outsiders will try to sort them into one group or the other.



Photograph by Johannes Rascher (2007).

While on the ward for a course of IV antibiotics, two young people with CF went out shopping. In this image, you can see the plastic tube of the IV access protruding under sleeve of the woman's right arm. While not officially sanctioned, health care providers sometimes tolerate such excursions, as they enhance participation in life. I am fond of this image, as it reminds me of the flexible approach of the CF ward, as well as of the precarious aspect of visible normality in people with CF from the perspective of outsiders.

The ambivalence of visibility obliges patients to negotiate conflicting priorities that can only be reconciled temporarily and in part. Reflecting upon these negotiations longitudinally, with consideration of how they evolve over the course of life, shows that a patient's tactics have undergone evolution over time and in response to evolving therapeutic regimen, whereby they shape identification. Identification as a person with CF changes when CF remains invisible, and therapy has become unproblematic. In this regard, one particularly interesting narrative to emerge from this study was that of Magdalena, a 32-year-old woman with CF. She spoke openly and energetically as we talked about living with a chronic illness, and how life with CF had evolved since her childhood. Asked to describe the experience of growing up with CF to people unfamiliar with the condition, she introduced the theme of migration as a metaphor.

"When I was an adolescent, I said, 'Hi my name is Magda, and I have cystic fibrosis'. I was rather harsh and quick, but this was a process of identification. [...] Today, I consider my cystic fibrosis to be like my migrant background. It made me who I am, but it doesn't define me. Now, for half a year I've been taking a new medication[a recently introduced basic defect modifier that is specific for certain mutations] and currently you may not notice my CF. A while ago I met a young man, and we had a couple of dates. I only told him on the fourth or fifth date that I had CF, and he said he hadn't noticed. [...] A couple of dates later when we were eating together, I took pills, digestive enzymes. And he said, 'I completely forgot that you have this CF'. That would not have been possible half a year ago, because now I don't have to cough anymore. Despite a lot of therapy, and especially towards the evening, [I would have to cough] if a lot of sputum had built up. [With this new medication] identification with the illness will be different in the future, just as the question what my environment notices of my illness."

Interview with Magdalena (2021).

For Magdalena, as with many young people I encountered in the course of my research, CF was not only a medical condition that she had, but also an 'identification'. While this identification did not mean she was living according to the dictates of some convention, her illness was not something that she concealed, but rather spoke about openly. She learned that "it is no use hiding; people will find out anyhow". The degree of visibility declined, however, with the advent of new therapies, and this in turn changed the awareness of others about her illness, and thus changed the identification.

Over the years, I came to understand living with CF like a temporary migration into the land of the healthy.

The daily process of migration through therapy is hard work. Belonging to the world of the healthy is revocable at any moment. Belonging is liminal, being neither strictly to the group of the healthy, nor to the group of the ill. By this, I mean that therapeutic work helps people with CF to become immigrants to the land of health. The term derives from the self-understanding of some people with CF, i.e., it is an emic concept, arising from the native point of view. This neatly inverts Sontag's metaphor of illness as migration to the kingdom of the sick. Unlike in Sontag's cultural analysis of tuberculosis and cancer, the metaphorical process of migration in CF is not from health to illness, as people with CF have always had CF. The metaphor of entering the land of health differs from the concept of "biosociality" as developed by Rabinow.[30] While entry temporarily effaces membership in or identification with the group of the ill, despite the shared biomedical features, therapeutic migration is the counterpart of biosociality. According to the progression of the illness and developments in therapy, the migration needs constant re-adjustment. The process of migration from the land of the ill to that of the healthy never comes to an end, but is always temporary and subject to revocation. For people like Ricky, Maja and Magdalena, we might think of it like a non-permanent visa. This metaphor differs importantly from the concepts of "biological citizenship",[31] "pharmaceutical citizenship",[32] and "therapeutic citizenship".[33] Therapeutic immigration does not lead to citizenship, be it biological, therapeutic or pharmacologic, as might be said of people taking a medication. Moreover, those concepts postulate a status coming with a set of rights and responsibilities that derive from taking a medication, or from adherence to therapy. The identity as an immigrant to the land of health remains liminal, since one occupies an intermediate and shifting position poised between illness and health. For people like Adriane, who chose not to use the 'visa', hiding therapy comes with the additional cost that no particular rights available to chronically ill or disabled people derive from this liminal status. For them, I propose that their immigration remains an asylum, a position of security that is revocable at a moment's notice.

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