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Experiencing ‘Health’ despite ‘Illnesses’

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Based on a personal story, I explain three reasons why it is important that caregivers pay attention to the life-story and search for meaning of a person with a chronic disease in the middle of his/her life, during the diagnosis and treatment process. 1) Being chronically ill can disrupt the chronology of a life-story, whereas seeing cause and effect in a life-story can give people a sense of meaning. 2) This sense of meaning can result in an experience of health, despite illness. 3) However, during the diagnosis and treatment process there may be power tension between the caregiver and the care-receiver. Giving attention to these things and what it means to be sick, can overcome this.

Therefore, I also explain the possible contribution of reflexive spaces against power tension and towards the attention of the life-story and search for meaning of a person with a chronic disease in the middle of his/her life.

Lessons for Practice

- More attention should be given by caregivers to the life-story and search for meaning of a person with a chronic disease in the middle of his/her life.
- Caregivers should be more aware of potential power tension between their professional opinion and the needs of a care-receiver given his/her life-story.
- Reflexive spaces could help to emphasize the life-story of the care-receiver and can help to reduce possible power tension.

Keywords: chronic disease, care ethics, reflexive spaces, life story and search for meaning

Being chronically ill has influenced my life-story

I am part of the 58% of the entire Dutch population who has one or more chronic conditions. Many think that only elderly have chronic disease, but 40% of all the chronic ill people was younger than 24 in 2019 (public health and care, 2021). These chronic diseases do not necessarily cause early death, but they do have a major impact on the daily lives of these people. My life-story confirms this.

When I was a 12-year-old girl, after years of searching they discovered that I had Celiac disease. From one to the other moment, my whole life changed. The doctor told me I had a chronical disease of the intestines, which can only be treated by the elimination of gluten in my diet. After a year or so, I would be healthy again and life a normal live: no further impact. So, good luck with that. I did not even know what gluten were.
But 'no further impact' could not have been *more* wrong. Trying to eat healthy and delicious food without gluten was one thing, but I was not prepared for the rest. From now on I always had to bring food for myself, or give explicit instructions, felt left out, or placed in a negative center during social occasions. Not to speak about the fear to fall ill from things other people enjoyed eating. For these reasons, I only saw this disease as a 'social matter'. My body was 'healed', right? However, after a few years I recognized that not all the symptoms were ever gone, I just had ignored them. Some symptoms had come back, even though the test results constantly showed that my body was 'healed'. Slowly I dared to face the fact that I was chronically ill and that this disease was not 'simply' a social matter. Because even if I would deny it or describe it differently, in fact I am chronically ill. Through this I came to see how this disease had influenced many choices in my life.

For instance, the influence of this disease on my psychological wellbeing: the anxiety to eat, the fear to fall ill, the urge to control and the unhealthy amount of adaptability towards my social environment because 'I was afraid to be a burden'. But also, the enormous amount of psychological resilience, the perseverance never to give up and above all, a way of looking at life that was not quite common for adolescences; a large amount of gratitude towards small things. Physical health was not the most important thing for me, it was the search for being meaningful and being grateful despite illness.

In some ways the recognition of the fact that I am chronically ill, helped me to take myself seriously. However, I do not view myself as a 'sick' person, because despite the physical illness I still experience health through searching and experiencing a life that feels meaningful.

The importance of a chronological life-story

But experiencing health through meaning is difficult when I feel as if my life-story in relation to the disease is inconsistent. All people have the necessity to tell a chronological life-story. It helps us frame the elements of our personality. Besides, seeing cause and effect through chronology, helps us to make sense of 'disruptions' in our life-story, like illness or distress. This helps us to re-establish consistency and meaning in life, which contributes to processing difficult experiences (Zimbardo, Johnson & McCann, 2013).

Being chronically ill is an inconsistent experience, which might lead to distress

My experience is inconsistent because there is no 'end' with this disease. I cannot construct this experience of being ill in my history; looking back at it and thinking 'right, that *was* hard, and I do understand why it *was* hard and how it *has* influenced my life, lets now deal with the present'. This makes chronical illness a different experience from for instance an infection disease. It will always be there!

I therefore experience not only growth, stagnation, or neglect towards the experience, but also fallback, because I must cope and adapt towards the illness depending on the time and space in my life. Often, I experience growth, fallback, and everything in between in the same moment; I want to fight, flight, and freeze at the same time. This can be very confusing. It is like grieving; it never ends, but you *must* learn to deal with it over and over again, depending on the kind of confrontation. This could result in personal growth, but also in distress and anxiety. Every time I think that I have peace with this disease and focus on the thing that it brought me, instead of the things that could have been, I get confronted with it in a negative way. Then I experience incomprehension, condemnation, or fear that my body will just fall sick again. Every time I think 'now I know how to relate to it the next time' and see "the value" of it, life offers new challenges. This sometimes makes me feel like I am back where I started. As if all my resilience is gone and I am too tired to 'fight' again. These changes in experience as to the disease is threatening in itself. What if my perseverance is ever used up? Can I trust on my resilience throughout all the inconsistency of life? Will I always be able to keep searching meaning despite this disease?

So, an experience of being chronically ill can be very inconsistent. According to Marsman (2021) and Boyer (2021), who both suffer from cancer, it is therefore logic that this experience leads to questions of meaning, which could lead to distress.

Life-story, meaning and health

Therefore, it is important to give attention to the life-story of people with a chronic disease, during the diagnosis and treatment process, so it can contribute to a feeling of meaning, and therefore a feeling of health. Because even though people are chronically ill, they can still *experience* health if they feel they are living a meaningful life (Huber & Jung, 2015). 'Health' not as a biomedical state, but also an interpersonal experience towards your own life. This could be explained by the idea of Frankl (1954) that the 'will to meaning' is the essence of being human; we cannot life without it, because it is what drives us.

Besides, meaning also contributes to *psychological* and *biomedical (physiological)* health. Early finding of a study of Ryff, Singer & Love (2004) suggest that a sense of purpose results in lower levels of pro-inflammatory cytokines, cardiovascular risk, daily salivary cortisol, and longer duration of REM sleep in ageing women. Fogelman & Canli (2015) showed a faster recovery to pre-stress baseline levels of cortisol due to purpose. And Schaefer, Boylan, Van Reekum, Lapate, Norris, Ryff & Davidson (2013) showed that 'having purpose in life may motivate reframing stressful situations to deal with them more productively, thereby facilitating recovery from stress and trauma'. These are hopeful effects of a feeling of meaning, especially for people who are chronically ill.

Attention to meaning is just as important as attention to the biomedical side of illness

It is however common in regular care, to only focus on biomedical treatments. Like in my story: 'When you do not eat gluten, you will be cured'. Even though this was biomedically true, this led to *power tension* (Tronto, 1993) between the biomedical advice of the caregiver, and my personal needs as care-receiver. *Most* of my caregivers considered good care for my biomedical condition but did not consider my life-story and search for meaning in their advice. Also, my caregivers did not consider my life-story when I was older and started to talk about my story. This led to a feeling of not being seen and understood; sometimes even the feeling that I was reduced to an irreparable machine.

This is worrisome, because we (myself and many with me) are as care-receivers vulnerable and depending on the expertise of the caregiver (Tronto, 1993). With a chronic disease, the 'machine' cannot be repaired (Barry & Yuill, 2016). And even though I am happy the disease symptoms are treatable; it has further impact besides the biomedical. It is therefore necessary to talk about what it means *to be sick*, and what kind of treatment fits your life-story and search for meaning. Attention to someone's life-story and the impact of chronic disease on the search for meaning, could therefore overcome this power tension, and even contribute to a feeling of health despite illness.

Life-story as a starting point in the diagnosis and treatment process: how *reflexive spaces* can help

Reflexive spaces (Wigg, Aas & Bal, 2019) could help caregivers and care-receivers, to give more attention to these things. During my master thesis I conducted research into how caregivers contribute to quality of life, of which *meaning* is part, of people with dementia in the palliative phase. I think we can learn something of use from the things I discovered, for the diagnosis and treatment process of people with a chronic disease who are still in the middle of life. The caregivers in my research were very aware of the integral connection between experiencing/searching meaning in life and the biomedical condition of someone. They reached these insights with a multidisciplinary team in so-called *reflexive spaces* (Wiig, Aas & Bal, 2019). These are *spaces* where people collectively reflected in a metacognitive way on their own actions and that of others. The role of their own frame of reference in the care process was also reflected. It was a safe and open place where people were open to learning through feedback, through dialogue and telling stories. Because they reflected in this way, they reached together with the care-receiver (or his/her family) the most appropriate care-vision for the individual, given his/her life-story. Their shared vision became a protective factor for the possible subjective judgment of one caregiver. This was because they became aware of the possible *power tension*, which allowed them to influence negative effects of this. This made the life-story of the care-receiver the starting-point of the treatment.

Conclusion

I showed the positive results of the use of *reflexive spaces* towards possible power tension between the caregiver and the care-receiver. Even though the care settings of care-receivers with dementia in the palliative phase and care-receivers with a chronic disease in the middle of life, are hard to compare, both groups need attention from the caregiver towards their life-story and search for meaning. Giving attention to the life-story of people with a chronic disease, can result in a less inconsistent experience. This may lead to a greater sense of meaning through chronology. Through this sense of meaning, people can still experience health despite their physical illness.

The use of *reflexive spaces* could be helpful to give more attention to this. It could overcome possible power tension and make the life-story and search for meaning of the care-receiver the starting-point of the treatment.

> *"My history, present and future are all influenced by this inconsistent experience of being ill, even during moments I feel completely healthy. Even though I always strongly resisted the idea that I must identify 'myself' with this disease, after 12 years I can no longer deny that disease is part of my identity. The fact that this disease will always be shaping my life, is the only consistent factor in this inconsistent and insecure experience. That is why I search for meaning through my disease, so I feel like being 'more' than just a person with a disease that never ends."*
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> *A.M. Hazenoot-Hoorn, 2021*

A note from the author

I'm Merijne Hazenoot-Hoorn. I'm 25 years old, married and I live in Arnhem. I have done several studies: Apropaedeutic year 'Applied Psychology', bachelor 'Health and Society', pre-master 'Ethics of Care and Policy' and currently I'm finishing the Master 'Healthcare Management'. In the future I hope to do a PhD in which I could apply the knowledge of the studies mentioned. For now, I am busy starting my own company ('Significativa': Latin for 'meaningful'), in which you can consult me about questions of meaning in the context of healthcare and education. I do research and give advice though storytelling.

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