

“Getting sick has been good to me, not bad”

Understanding the experience of growth in face of adversity

Silke Hoppe

In the literature and public opinion chronic illness is mostly presented as a negative experience. However, this article shows that people can experience their illness also in a positive way. Posttraumatic growth and adversity-activated-development are concepts, which derive from psychology and describe a positive transformation after a challenging life-event. People who experience personal growth have an increased appreciation for life and may change their priorities and approach to life. By means of empirical examples of people who have been diagnosed with Multiple Sclerosis the author shows how people positively experience their illness and may grow from this experience. Further the author attempts to answer why some people experience personal growth and development after being diagnosed with Multiple Sclerosis, while others struggle with their illness.

[chronic illness, illness experience, posttraumatic growth, adversity-activated-development, liminality, Multiple Sclerosis, Dublin]

Imagine you would be diagnosed with a chronic and progressive disease, a disease which cannot be cured and with which you would have to live for the rest of your life. Your symptoms would worsen over the years, leading to increased disability. For most people this would probably be a frightening idea. In the literature about chronic illness this attitude is reflected. One can find a spectrum of negative experiences resulting from chronic illness. People may experience a loss of self, their body loses its functions (Charmaz 1983, 1991, 1995), their self worth and identity are assaulted (Bury 1982, 1991), people have to face isolation, dependence, marginalization, exclusion (Ware 1999), stigmatization (Jacoby et al. 2005; Susman 1994), unemployment, financial insecurity, depression or even suicide (Thompson 1998: 190). During the last decades the focus slightly shifted and more attention is paid to courage and hope, reshaping the self, regaining control, finding meaning, empowering potential, normality, and discovery (Thorne & Paterson 1998: 175). Albrecht and Devlieger (1999) point out that many people with serious and persistent disabilities state to have a good quality of life. The authors refute the assumption that people who are diagnosed with a chronic illness live an undesirable existence. However, nowhere in the anthropological

literature about chronic illness, I found accounts of people who expressed that their illness changed their lives to the positive. Indeed, the statement “getting sick has been good to me, not bad” at first seems contradictory and strange. How does a person who has been diagnosed with a chronic and progressive illness come to such a conclusion?

In this article I analyze narratives of people who state that they experience their illness in a positive way and I attempt to explain why some people are able to positively transform their illness experience. In order to answer this question I present three empiric examples of people who have been diagnosed with Multiple Sclerosis and who positively deal with their illness.¹ In the following I apply the concept of posttraumatic growth and Adversity-Activated-Development in order to describe and analyze people’s experiences. Both concepts derive from psychology and describe the experience of positive transformation after adversity (Tedeschi & Calhoun 2004; Papadopoulos 2007). Yet, as there is relatively little literature on the concept of Adversity-Activated-Development, the article predominantly discusses the concept of posttraumatic growth. In order to answer the question why some people are able to positively transform their illness experience I apply the concept of liminality. I end with a conclusion and the implications of my research.

The empiric examples I use derive from my fieldwork in Dublin where I studied twenty people who have been diagnosed with Multiple Sclerosis. I interviewed the majority of my informants two or three times spread over a period of time. By gathering their narratives, meeting people more than once, observing their behavior, and speaking with family members I tried to come close to the illness experience of people. As I have an illness similar to Multiple Sclerosis, I used my own experience as a tool to deepen the knowledge gathered in the conversations with my informants. If people, for example, stated they were able to deal well with their condition, but after the conversation I left with negative feelings, I surmised that people might have left out negative experiences in their narratives. Whereas when I left with a positive feeling and people also mentioned negative aspect of their illness, I used this as an indication that people do not neglect the negative aspects but are indeed dealing well with their situation. This, of course, is not to say I entirely relied on my own experience, but I used it in combination with other methods in order to gain more insight into people’s experiences.

Experiencing personal growth

Yeah, there was, there was, there was, yeah there was, yeah there was a reason why I got MS, yeah. To slow me down [laughs] or to bring out this different person I am. Because I am a totally, completely different person compared to how I was. Before I got sick at all, I was a bastard. I was a right shit, you know what I mean, a street angle and a house devil. I don’t know whether you heard that expression. You see outside, he is a lovely man and in the house I was a really different person all together. I was the boss; everything had to be done my way. That’s gone out of the door. I am somebody else now, you

know what I mean. What brought me down to reality, that there is more to life and you know what I mean. I suppose, it showed me what reality is. I am lucky to be alive now. I am lucky to be able to do what I am doing. I am delighted to be able to do what I am able to be doing. I am very proud of what I am doing and hopefully I can get on and do an awful lot more, yeah.

This is the answer Alex gives to my question whether there was a reason why he got sick. Alex is in his mid fifties, married, and has two sons. For twenty-seven years he was a chef and represented Ireland at the cooking Olympics. When he got his first symptoms about six years ago, his life changed completely. He had to stay one and a half years in bed waiting for an appointment with a neurologist, not knowing what was wrong with him.² This period was very difficult for him and he thought about committing suicide. When he finally got his diagnosis he was relieved. "It was quite a relief. At least I knew what was wrong with me. I thought I had cancer. What can you do? You are lying there, you can't get up. It was a struggle to get a cup of tea". By stating that he wanted to commit suicide he underlines how drastic this transformation was for him. At first sight his illness is not visible. He suffers mostly from fatigue and during the night from muscle spasms. Because of his illness his lifestyle changed a lot.

My life changed completely. It showed that I was an outgoing person, sports wise. I loved sports, loved being fit, everything. I can't do anything of that now. The best I can do is go for a walk. I don't like swimming anymore. Don't ask me to go, I won't go. No, I can't do the things I'd loved to do, not anymore. I can't do it. Cycling, no. Swimming, no. Hockey, I was big into Hockey, enjoyed it, played Rugby. Now I do the soccer coaching here, I bring the lads down, watch them play. I don't think I'd be able to kick a ball now, my balance wouldn't let me. My life changed completely, yeah it did. I had to readress, I suppose I had to be reborn. I had to be reborn, I had to change my life completely. Where I would have been an outgoing night person, enjoy life, enjoying life to the full, party wise and all that same song, everything...I can't do that anymore now. But I don't mind. I am quite enjoying being at home now and sit down with a nice glass of wine. It's all now completely different going from one extreme to the other. Yeah, I had to readjust my life.

In spite of these big changes Alex comes across as a positive person. In the first minutes of our conversation he says: "Getting sick has been good to me, not bad. I know it is a strange thing to say, but I worked on it. I got out seeing what was out there". He argues that his illness is a challenge and that he likes challenges. His way of dealing with his illness is to not let the illness affect who he is and not to let it hold him back. According to him his wellbeing has been enhanced by the Emotional Freedom Technique and by Brain Gym, which are based on the principle that via tapping on the meridians of the body psychological and physical problems can be solved. His biggest change would be his outlook on life. Before he got Multiple Sclerosis he worked eighty hours a week and now he works at a learning centre for people with disabilities. This work gives him a lot of satisfaction. He states: "My life is good and I am enjoy-

ing it". He does not deny that he has Multiple Sclerosis, but he tries not to let it affect his life too much.

According to Alex his illness was necessary to make him change his priorities and have a different outlook on life. But in addition he also changed his whole personality. In a second interview he states that he would not know whether he would want to live without his illness. "It's frightening, what am I going to do if I don't have MS?". His fear is that he will become his old self and return to where he was before he got Multiple Sclerosis. It is striking how much his illness has become intertwined with his personality and life. I have to say that my second conversation with him took place directly after he has visited an EFT workshop and that he apparently thought a lot about it. The people organizing the workshop told him that they could cure his illness but that he would be holding on to it. Obviously that strongly shaped the way he talked about his illness experience. Probably if I met him a bit later and asked him about it, thoughts about curing his illness would have moved to the background and lost importance as there is no cure for Multiple Sclerosis from a mainstream medical perspective. In spite of the differences he experiences with his illness the advantages of his MS seem to compensate for the problems. Although Alex also states that he is happy to receive financial support of the government in form of tax abatement and allowances, it seems that this is not the reason why he is able to deal so well with and even feel grateful for his illness.

Another informant, who in some aspects has a similar background to Alex, is Samuel. He is in his mid-forties, married, and the father of three girls. His symptoms mostly consist of fatigue and balance problems. In the beginning of our first conversation at his home he states that MS has been a life-changing event for him. Half a year ago he had to give up his work as finance director in a stock company. Abdicating his work was a difficult step for him because he has invested many years of his life building up a career. However, on the other hand he emphasizes that he is now able to spend more time with his family and get to know them better.

I had to search for a new, a new goal, a new set of goals. And I suppose those goals, they have been in various forms, obviously I know my kids better, I know my wife better, and we are all, I think, happier and more comfortable. My wife had to change her work style too. She is at work this morning. I am doing a course, a literature course in UCD at the national library.

Being diagnosed with Multiple Sclerosis changed his whole perception of the world. According to him this change was brought on by an intensive dose of steroids, a drug against the symptoms of Multiple Sclerosis. Samuel told me that he had been living his life from a negative perspective. Life for him was a battle and every morning he had to get up and fight. He was striving for perfection and thereby procrastinating because he was never content. While pretending to the outside world that he led a happy life, he was depressed and did not feel worthy as an individual. When he was on those strong drugs he went into a sort of shock and realized that the way he perceived the world was only his perception; it was not necessarily reality. As in the case of Alex

the positive changes his diagnosis brought overshadow, at least for the moment, the difficulties caused by his illness. Although his change of mind was induced by the help of drugs the effect was very powerful and made him experience not only his illness but also reality in a different light.

To a certain extent Samuel believes that he contributed to his illness because of his lifestyle.

Nobody knows how a person gets MS, how I got MS, how anybody else got MS. But if you asked me, if I had a crystal ball or if any God had a crystal ball...it was because you lived in this strange world of fear and that fear has led your whole system in overdrive. I lived in overdrive for forty-five years and as a consequence you're burned.

He expresses carefully that he was glad to get the wake-up call which made him perceive the world differently. In spite of his fears about the future progression of the illness and his family's financial security, Samuel has become less stressed about it and has fewer worries. Furthermore, he puts his illness into context.

When I was telling, we had dinner last May, at which I told them all that I had MS and that I was not being at work and all the rest of it. And Claire was there at the table, and she didn't quite, she knew I was saying something important, but not quite what. And Claire, age 35, with Down syndrome turns to one of her sisters and asks her 'is he dying?' And she said, 'no, no, no, don't be silly'. 'Well, what are you all worried about then?'. That actually captured and put it right in context...so simple, yet so profound and she is absolutely right, you know. Nobody is dying here. It is just a change of life. But it is not the end of it. Hopefully I will still be able to say that in ten years time, you know. But it does put things in context.

Thus, although he is afraid that his present attitude may change when his illness has progressed, at the moment he can relativize it. Yet he expresses that in the future he might think differently about it. Samuel comes across as a well-educated person who has thought a lot about his transformation. This shows because when I call him to make an appointment he asks for some time to prepare himself for the conversation and gives me a handout in which his story with Multiple Sclerosis is summarized.

The narrative of Emily shows similar features. I meet her three times in the Multiple Sclerosis Care Center where she works at the reception desk. She is fifty-two years old and has three grown up children. After being happily divorced, as she puts it, she now has a partner with whom she is very content. Her first symptoms presented almost thirty years ago, but she was officially diagnosed in 1988. She uses a walking frame at her work and at home and a wheelchair for longer distances. Although she went through some difficult periods, especially during her divorce and before her home was adapted to her disability, she now experiences her situation mostly positively.

I'd always say I got a special grace. Everybody is so preoccupied with their home and everything that they lose sight of the important things. And I had to be with myself and maybe it gave me the opportunity to realize what is important. And as well as

my experience from my marriage and alcoholism; I know what is important. It is important how you feel within yourself, that you have peace of mind. And that's what I would spare for all the time and thank God I have it. And certainly I would have got that from the MS. If I hadn't had the MS I would be running around which I can still do, a bit of running. I said to my daughter when I didn't have my MS, I would have left this country... I was very busy. Busy, busy... Whereas it is more important to have peace of mind which I didn't have in my marriage. I have to reclaim my peace by addressing whatever, so I do think that I would have got that from my MS as well. Just being in touch with how I am feeling. I appreciate that a lot. I have a lot of gratitude for the things I can do, not the things I can't do. I would say, definitely it is from the MS. I am aware of how grateful I need to be considering what I have...I still consider myself as very well. Everything is good, thank God. Love is a huge thing. I have a lot of love.

She has a good social network and is in a happy relationship. Her friends are very supportive and helped her raise money to renovate her house so that she would have all the facilities downstairs. Emily says that people are very helpful and that she can rely on the help of her neighbors and family but also on strangers she asks on the street. She states: "I live everyday. I have everything I need, although I can push myself a bit at times. Socially I do a lot, socially, more than my friends maybe. I enjoy life. I went to a party last week". Although she mostly emphasizes that she is a person who 'does not think MS' and who is able to deal well with the situation, sometimes it seems that she is just neglecting the negative aspects. Especially in our second and third conversation it shines through that it is sometimes still very difficult for her.

They [her friends] would joke as well, because no matter where I go to, people would move for me. They would joke about this as well. The cripple gets all the attention. But it's a joke. Probably my way of coping with it, making fun of it. Seldom I would, very seldom I would get a bit emotional about it, when I am tired. I go for acupuncture every Tuesday for myself...Just for a little moment I would get a little emotional and think that it is tough and only at that time, but for the rest it is okay. And it is tough, but I don't make it tough.

This quote shows how she is minimizing the negative aspects by using the words 'seldom', 'a bit' and 'little'. But on the other hand she has to admit that the situation is 'tough'. By saying that she does not make it tough, she wants to give the impression that she is in control of the situation.

Emily states that her MS was a "grace of God", because it made her focus on the important things in life. In addition she believes that God would not give her anything with which she would not be able to cope. Like Samuel she says it is not fortunate that she has Multiple Sclerosis, but it changed her life for the better. She reflects that her illness made her more grounded emotionally. Although her illness is affecting her role as mother physically she has the feeling that now, in contrast to when she was married, she is better able to care for her children emotionally. Sometimes it seems that she plays down the negative sides of her illness, but in general she gives the impression that she is content with the situation. It seems that her marriage with an alcoholic

husband was much worse than her illness. She now seems to have regained control over her life and also to some extent over her condition. By focusing on the positive aspect of her illness and by being pleased with small things in life she is able to deal with her situation well. At first I wondered whether Emily is denying the negative consequences of her illness. But after our last conversation, I believe that she is aware of and accepts the negative sides. In this section I have presented three narratives of people who positively deal with their illness. In the following part I will theoretically discuss their experience.

Theoretical analysis of personal growth

The narratives of those people all depict a positive transformation. People whose narratives belong to this category feel their life changed for the better as a result of their condition. They changed their priorities and approach life in a positive manner. What those people experience can be termed posttraumatic growth. It is defined as an “experience of positive change that occurs as a result of the struggle with highly challenging life crises” (Tedeschi & Calhoun 2004: 1). Traditionally the focus with regards to traumatic events has been on the psychological and physical problems that may result of it. According to Tedeschi and Calhoun this has led to a negative bias in analyzing the outcomes of traumatic events. However, the assumption that suffering can lead to positive changes is thousand of years old and appears in many traditions. Research shows that a minority of people experience growth as a result of a major life crisis. This does not mean people do not experience problems, but rather that distress and growth coexist.

Growth comprises an element of transformation. People not only react to the traumatic event, but change their attitude or behavior (Tedeschi & Calhoun 2004: 1-4). “What makes these experiences transformative seems to be that they have this affective component, so that the lessons learned are not merely intellectual reflections” (ibid.: 5). Thus, emotions play an important role in this transformation. People who experience growth after a distressing event share an increased appreciation for life, change their way of approaching their daily lives, and may change their priorities. Relationships can become more important and meaningful for people. They realize for example who their real friends are and how supportive they can be. This could signify that they lose old friends, but build up closer relationships to people who have a similar fate. Another aspect of posttraumatic growth is that people perceive an increased personal strength. Moreover, people might forge new paths in their lives, for example by changing professions. Often these aspects contain a paradoxical element. In spite of more restrictions people experience more freedom. This can be applied to people who have to use a wheelchair, but who are then more willing to take risks and explore new paths (ibid.: 6). One can say that people who experience posttraumatic growth used their illness as a springboard for personal development (Tedeschi et al. 1998: 1). Finally it is important to note that “the events themselves, however, are not viewed as desirable – only the good that has come out of having to face them” (ibid.: 7).

What Tedeschi and Calhoun termed 'posttraumatic growth', Papadopoulos describes as 'Adversity-Activated-Development'. "AAD refers to the positive developments that are a direct result of being exposed to adversity" (Papadopoulos 2007: 306). Just like Tedeschi et al., Papadopoulos criticizes the predominantly negative discourse around trauma and the tendency to medicalize and pathologize suffering. In contrast to the concept of posttraumatic growth, Adversity-Activated-Development does not assume that people have been traumatized. Another difference is that Adversity-Activated-Development does not suggest that growth only occurs after a traumatic event; positive development and adversity can coexist. Furthermore, positive development after adversity does not necessarily occur in a chronological order. People who experience adversity may display different positive and negative responses at the same time (Papadopoulos 2007: 307, 310).

With regards to the experience of Multiple Sclerosis the concept of Adversity-Activated-Development seems to be more appropriate than the concept of posttraumatic growth. First it does not assume that people have been traumatized, and second positive development or growth can occur during persisting adversity. For people with Multiple Sclerosis the diagnosis can be a traumatic experience, yet, as their illness progresses they are confronted with ongoing adversity. However, both concepts describe the same phenomenon. Both differ from the concept of resilience, which "refers to a dynamic process encompassing positive adaptation within the context of significant adversity" (Luthar et al. 2000: 543). In contrast to resilience, posttraumatic growth includes a transformation which changes people's life qualitatively (Tedeschi & Calhoun 2004: 4). Similar, Papadopoulos states that people whose experience can be described as Adversity-Activated-Development do not only bounce back after a traumatic event but people display new characteristics which they did not have before they were confronted with adversity. Papadopoulos criticizes that in the literature Adversity-Activated-Development and resilience are not being distinguished, but are ascribed to the same category of non-negative responses (2007: 308). Concluding, posttraumatic growth and Adversity-Activated-Development are useful concepts which provide a framework to analyze people's positive experiences with adversity. Those concepts call attention to the fact that people who confront adversity not only experience problems and difficulties with their situation, neither are they only able to return to their old life; their lives can become qualitatively different and more valuable to them.

Yet, some scholars see the experience of posttraumatic growth and thus also the experience of Adversity-Activated-Development as a coping strategy or as an illusion. Taylor and Armor, for example, argue that the experience of posttraumatic growth is a "positive illusion" (1996), which can have protective psychological effects that help people to better deal with their situation (Taylor et al. 2000: 100). In earlier works Taylor found that "when faced with threatening information or stressful events, people often respond with mildly distorted positive perceptions of themselves (self aggrandizement), an exaggerated sense of personal control, and overly optimistic expectations about the future" (Taylor & Armor 1996: 873). One might question whether what people describe is real growth or just a positive illusion. Yet, as my informants who experience posttraumatic growth have reflected well about their situation and

also mentioned negative aspects of their illness, I am of the opinion that for those people the experience is real and that they actually changed their priorities and outlook. One could furthermore argue that the opinion of critics who see posttraumatic growth merely as an illusion is shaped by a negative bias. Why is it not possible that people really grow out of a traumatic experience and gain a greater appreciation for life and a more positive outlook on life?³

Explaining personal growth

Instead of discussing whether the experience of posttraumatic growth is real, a more important question is why some people experience posttraumatic growth after a challenging event? As Tedeschi and Calhoun (2004), Papadopoulos points out that “transforming adversity into positive development is a phenomenon that has always been known to humans” (2007: 306). But how can one explain that some people transform in a positive way, while others predominantly experience losses and problems with their situation? In order to explain why people experience their illness so differently I analyzed different factors. I first analyzed to what extent lifestyle changes in the social network, employment and leisure time impact on the way people experience their illness. Thereafter I reviewed individual factors, such as, time of diagnosis and age, gender, functional disability, dependence, and visibility. Finally I debated the role of spirituality in the illness experience.

Analyzing the narratives of people who experience posttraumatic growth one can observe several similarities. People with those narratives are all in a relationship, they either work or have meaningful leisure time activities, and two of them are religious and believe that God helps them on their way. Yet, as people who struggle with their condition also were in relationships, had an employment or believed in God, these factors do not explain well why some people transform in a positive way. Similarly, the other factors do not satisfactory account for the differences. Time of diagnosis and age, gender, visibility and functionality disability do not help to predict how people experience their illness. People with narratives describing posttraumatic growth were diagnosed in different periods and had different grades of disability. While Samuel does not need any walking aid, Alex is able to move around with the help of a walking stick and Emily needs a wheelchair for longer distances. One could assume that the more severe the functional disability, the more problems people experience. In the literature there still is a general agreement “that people with more severe MS have less favorable psychosocial outcomes” (Dalos et al. 1983; McIvor et al. 1984; Zedlow & Pavlou 1984, in Wineman 1990: 295). Yet, the relationship between symptoms and the experience of the illness is very complex. Robinson states that “there is no simple relationship between physical disability and the subjective experience of multiple sclerosis” (1988: 48). In a study Lynch et al. found “no evidence of an interaction between disability and any of the psychological variables” (2000: 414).

Deconstructing illness narratives in a semi-statistical way assumes that there is a direct relationship between one or two factors. But reality is more complex; although

those factors to some degree shape the illness experience, it is impossible to determine one or two factors which can explain the majority of differences. The relations between these factors and the impact they have thus differ for every person. Because of the restrictions of this article, I cannot fully demonstrate that the importance of these factors is different for every person. Yet, in general people who experience post-traumatic growth have more protective factor, like a good social network, employment or the belief in God.

To better understand why some people are able to transform their illness experience in a positive manner, I applied the concept of liminality. Liminality is one of the three stages of rites of passage which were first described by Van Gennep (1977: 11). Turner (1967) further developed the concept of Van Gennep and especially focused on the liminal phase. He coined the term 'betwixt and between' to describe the ambiguous position people reside in. Turner argues that people in a liminal phase are structurally invisible. "They are no longer classified and not yet classified" (Turner 1967: 96). He emphasizes that people in a liminal phase are considered as unclear and contradictory. Liminal beings are symbolically sexless and have no status, rank or any characteristics that would distinguish them from their fellows (ibid.: 98). Yet, the liminal phase also offers possibilities. "Undoing, dissolution, decomposition are accompanied by processes of growth, transformation, and the reformulation of old elements in new patterns" (ibid.: 99). Furthermore, liminality can be seen as a stage for reflection.

The concept of liminality can be applied to describe the situation of people with a chronic and disabling illness. According to Murphy et al. disability is an "in-between state for the person is neither sick nor well" (1988: 238). People with a disability often experience social invisibility, simultaneously noticed but unacknowledged by society. Moreover, just as neophytes who go through a liminal phase, people with a disability are perceived as asexual (ibid.: 240). Navon and Morag show that people display different reactions to medical treatment of prostate cancer; some deal more positively with their illness than others. The authors disagree with scholars who argue that those differences can be ascribed to methodological differences, and argue instead that the anthropological concept of liminality can provide insight into the situation of chronically ill people. Liminality applied to chronic illness means that people are not able to "classify themselves into culturally available categories" (Navon & Morag 2004: 2337). Other characteristics include senses of disorientation, loss and uncertainty (Little et al. 1998: 1485). Again, authors applying the concept of liminality sketch a rather negative picture. I argue that people who are being diagnosed with Multiple Sclerosis go through a phase of liminality, but may be able to transcend it. People who reside in liminality predominantly experience losses and problems with their illness. On the other hand, people who experience posttraumatic growth seem to have used the liminal phase for reflection and have left it.

While the latter resides in liminality, they experience a turning point which marks the way of out their liminality. Turning points are important life events which can be positive or negative.

According to Bruner (1994), turning points often carry an affective or moral message, are saturated with emotions, and are ultimately attributed to a change inside a person, such as a new belief or newfound courage, although they can be linked to changes in external events (King et al. 2003: 186).

King et al. apply the concept of turning points to people with disability, arguing that turning points can take the form of a new attributed meaning or understanding that transform a negative experience into an experience of growth. This new understanding can involve accepting one's disability, redefining the self, creating new relationships, establishing independence and transcending limitations (ibid.: 198). By seeing an event in a different light and reframing it, a loss can be transformed into a gain (ibid.: 200). In the following I analyze the narratives described above with regards to the concepts of liminality and turning points in order to better understand how these people were able to transform their illness experience in a positive way.

Transcending liminality

For Alex (55) the time before the diagnosis was very hard as he had to wait one and a half years for the diagnosis. Since during that time he did not know what was going on with him, he even considered committing suicide. Back then he mostly had to lie in bed and was not able to work. Other social activities, like doing sports or meeting with his friends, were immensely restricted. During this phase he was mainly separated from society. His illness changed his life drastically.

Biggest change would be my outlook on life. Before I was sick I was just working eighty hours a week and suddenly, boom, you are lying in bed and watching telly and you see somebody else is doing your job. I think it brings you back to reality.

Lying in bed one day and seeing that his job has been replaced was a huge shock for him. This time can be described as a liminal phase as he did not have a clear position within society and he experienced a status loss and feelings of anger. Receiving the diagnosis was a relief for him because he finally knew what was going on with him. The ambiguity and uncertainty that he felt was resolved. Taking regular medication, he again was able to walk around and to work part-time. He applied for a position in an organization working with people with different disabilities. His current work might not give him such a high status, but for him it is very satisfying as he can see people developing and help them doing so. Alex illness experience depicts a turning point. He actively decided to change his outlook on life. An important prerequisite of this change was that he first acknowledged his reality and accepted it.

With regards to his work Alex was able to transform his state of liminality and to reintegrate into society. However, with regards to his family and friends he still experiences liminality. His wife does not let him do things, which assaults his position in the family. Yet, it is important for him to at least try. He emphasizes that he wants

to prove people wrong and show them that he is still able to do a lot of things. “The desire to prove others wrong appears to be a common helpful factor for individuals who experience a risk factor, such as disability or poverty, that is thought to limit their ability to succeed” (King et al. 2003: 198). Proving others at work or in his family might be a source of power for him. Alex tells me that he cannot have sex anymore, which frustrates him a lot at the moment. Not being able to have sex affects his male status. However, he reports that he has build up a better relationship with his family because he now spends more time with them. This might be a way to compensate for his sexual restrictions.

Analyzing the situation with his friends and relatives, he still resides in a liminal state.

Friends? My friends, I suppose, some wouldn't know how to treat me, some of them. Family at home, brothers and sisters. They don't know what I have, I suppose they don't know how bad it can be. Any friends I have they wouldn't know how to treat me. Is he sick, is he not? They would see me slowing down. How would they treat me? I suppose they wouldn't know many people who have a disability or MS...We have a car sticker, a wheelchair sticker, there is nothing fucking wrong with him...I suppose they don't know how to look at me at times, is there anything wrong with him. Is he for real? I suppose my friends would look at me that way, some friends.

But it seems that his transformation outshines the liminality he still experiences with his friends. His own personal development, at the moment, seems to be more important to him than being accepted by his friends for who he is.

Samuel's (45) narrative also describes personal growth. His diagnosis in 2007 was a life-changing event for him. He worked fulltime and his colleagues could contact him whenever they wanted. Yet, one and a half years after his diagnosis, he changed his priorities. His health was more important for him than his work, and he resigned. He compensated for the status loss by spending more time with his family and by taking a university course. In the process of his diagnosis he experienced a drastic transformation in his perception of the world.

I would definitely say it [MS] was a life-changing event that I experienced during that process. And I would say it turned me from someone who spent the first forty-five years in a negative world in a negative perception of the world and it never occurred to me that there was any other way to perceive the world other from that negative perspective. I was always looking at everything as a challenge, as something I had to battle with and I woke up like this every morning. I suddenly realized this is not the world. It is just my perception of the world and it never occurred to me that there would be another perception. I changed my view from a negative view to a realistic view.

This changed perception was induced by a high dose of steroids, which can prompt delusion, depression, or psychotic behavior. For him the drug did not have a physical effect, but rather the mental effect of making him perceive the world differently. In

the beginning he doubted whether his change was real and wondered whether he was living in a false world that would be destroyed in the near future. However, this has not been the case, and his new perspective enabled him to transform his relationship with his wife, his children, and his work colleagues. One can argue that his time in hospital resembles a liminal phase. Being isolated from his family and the community, and facing uncertainty, he was in a position to reflect on his life. Hallstein argues that the hospital can be a liminal place where people can reflect about their lives and the purpose of their existence (1992: 252). Samuel's transformation, according to him, was not a slow process but rather a sudden, drastic event triggered by drugs and occurring in the isolation of a hospital. This experience can be described as a turning point in his life. He expresses that after his change of perception he realized that in former times he was depressed and felt miserable, but pretended to the outside world that he led a happy life. He points out that only his wife knew it but that she could not convince him that his attitude was problematic.

Emily's (52) illness narrative illustrates a clear transformation from experiencing many difficulties with her condition to experiencing personal growth. Although she reports that people are very friendly when she is in a wheelchair she also expresses that there were times when she felt less feminine. In the wheelchair people cannot see how tall she is and the wheelchair in her eyes overshadows her beauty.

I think personally I do not seem an attractive woman in a wheelchair, maybe not a woman at all. Even when you have your walking you are more independent [and perceived differently]. I think when you're seen in a wheelchair, maybe you're seen as somebody that is not well.

When her partner introduced her to his parents she was concerned that his parents would look down on him, because he chose a 'woman in a wheelchair'. But this was not the case. Emily's sentiments probably result from a view expressed by society. What she describes are characteristics of the liminal phase. Her gender dissolves and she feels less like a woman. That time was very hard for her, and she was in denial about the limitations of her illness.

I cried a lot about things. I didn't have the money for it [renovation of her house]. I was very sad. I have a lovely home. I was very low at that time, I suppose because I was progressive and I was alone with my children. I am trying to be strong. It can be difficult being strong every day. Then you meet people asking you how you are and I would always say I am great. But I get tired being strong, not often, but there are times.

She stresses that during that time her friends saw her needs more than she could see them. Living in a house where she had to go upstairs in order to go to the toilet or to sleep was difficult for her. Emily says that it was very normal for her to say to her daughter that she should get 'mummy's potty'. Her friends, however, realized that the situation had to be changed. They raised money for her so that her house could be adapted to her needs. From that point on, things have become easier for her. Her active

social life and the strong support of her friends make it easier to deal with the situation. As she is happy with her partner and there are no problems with his parents, she again seems to feel more like a woman. With her friends and partner, her illness is not a large issue or at least she attempts to minimize it. Hence she has exited the liminal phase with regards to this social domain. Of course, this is not necessarily permanent; a break up with her partner or a shift in her friendships could change her whole situation and social position.

Emily mostly stresses her independence and enjoyment of life, but admits that she sometimes finds it difficult dealing with her restrictions and with the fact that she is the only one with Multiple Sclerosis among her close social network. Now she states that, in contrast to some years ago, her thoughts are free from focusing on Multiple Sclerosis. She points out that she has her life sorted out and therefore is able to deal well with her situation. Also, at the moment she still takes a light form of an anti-depressant in order to stay out of the 'black hole' she experienced a few years ago. Changing her priorities and focusing more on her family and partner, are for her positive results of her illness.

Because she has been in a difficult situation with her alcoholic ex-husband, she does not want to get herself in such conditions again and now only accepts good things in her life. Emily would say that her illness affected her role as a mother physically, but she thinks that she is now emotionally closer to her children and can take better care of them. In that way she can compensate for possible shortcomings. The only domain where she still experiences liminality is with her extended family. Her mother dismisses her illness and says that she 'at least does not have cancer'. According to Emily they do not want to listen to her and they neither accept her nor understand her situation. To conclude, Emily went through a period of liminality that she still experiences with her extended family and sometimes with her friends, but she has managed to leave this phase by changing her priorities and by giving meaning to her situation. The experience of a bad marriage has made her stronger as she does not tolerate bad treatment anymore. The fact that she has a good social network, is in a happy relationship, and believes in God seems to foster her positive transformation. As those empirical examples have shown, people do not necessarily transcend liminality in all areas of their lives. Hence, transcending liminality can refer to an incomplete process, which nonetheless has an important effect if it occurs in significant areas of life.

Analyzing what happens in a liminal phase can help us understand why some people are able to transcend it. According to Turner, transformation occurs when ambiguities and inconsistencies appear (Kapferer 1984: 5). Those ambiguities are characteristic of the liminal phase. Thus, as Turner suggests the liminal phase can provide room for reflection which can result in transformation. According to Boyd and Fales reflective thinking creates meaning and changes conceptual perspectives (1983: 100). "The process of reflection stimulates affective, cognitive, and even, behavioral changes" (Thorpe & Barsky 2001: 762). Moreover, self-reflection can be a characteristic which enhances personal growth (Stark 1994: 579). Reflection, therefore, can lead to a new evaluation of the situation and foster growth. According to Hallstein, the liminal phase is necessary for transformation, and special space needs to be created, for example in the form of psychotherapy, to aid this process. "That is, the initiate (or client in

therapy) is not necessarily transformed during the process, but *without* going through the liminal state, without the opportunity such space provides, there is *no* chance for transformation” (Hallstein 1992: 249).

Deconstructing the above narratives, it is striking that all describe a low period of being isolated from their normal social environments. Furthermore, they all state that before they were diagnosed they led an unhappy life. From their perspective, their lives appeared perfect to the outside world, but were miserable inside. Schouten argues that “[a] transition of identity begins with separation from some role, relationship, or other key component of the extended self” (1991: 421). This separation might occur when people have to spend some time in hospital or when people are not able to engage in social activities to the extent that they are used to. It seems that above informants used this liminal space for reflection and transformation. Their turning points occurred during liminality and mark the way out of it. Transformation, which happens on condition that people are open to change, involves a period of restructuring. As Canda points out, people might only experience the benefits of transformation such as insight, liveliness, a new meaning, and direction in life, when they break down their old self and social structures (1988: 207). He further states that “... ‘falling apart’ should not be stigmatized and penalized as a sign of weakness, deviance or dysfunction” (ibid.). Likewise he argues that people should not idealize ‘getting it together’ because such an ideology causes stagnation and repression. Canda concludes that “breakdown can lead to breakthrough” (ibid.). Hence, in order to transform people may need to experience ‘falling apart’. In summary, the liminal phase should not be seen as an entirely negative experience, but also as a space that offers possibilities and opens up new paths.

Transformation can also occur when suffering is made meaningful. Kirmayer argues that when one gives meaning to illness one can transform one’s suffering. “Meaning – any meaning – serves to turn back the tide of chaos and bafflement that confronts us in affliction” (Kirmayer 1994: 183). In a study Chiu argues that understanding oneself and giving meaning to suffering can help people who face unchangeable adversity (2000: 70). Egnew points out that when people reconstruct their identity and are able to find meaning they are able to transcend their suffering and to experience healing (2005: 259). Similarly, Papadopoulos remarks that giving meaning to suffering can be transformative (2007: 306). Thus, the ability to give meaning to one’s suffering could explain why some people are able to transform their illness experience in a positive way.

Whether people use liminality as a space for reflection and transformation is linked to their agency. Agency can be described as the capacity to choose behavior (Cokerham 2005: 55). Emirbayer and Mische define human agency as a process that is temporarily embedded because it is “informed by the past (in its habitual aspect), but also oriented toward the future (as a capacity to imagine alternative possibilities) and toward the present (as a capacity to contextualize past habits and future projects within the contingencies of the moment)” (1998: 963). With regards to people who have Multiple Sclerosis this means that they evaluate their situation by comparing it to the past and reflecting about what they are still able to do and how they can achieve

their goals in spite of their physical restrictions. Giddens (1984) defines agency as the capacity to process social experience and to act upon it. People who are able to combine their experience with knowledge, ideas and values are able to change their behavior and way of thinking. These abilities are also necessary for reflection. In order to transform their lives in a positive way, people might need to retreat from their situation and reflect on it, which can be a painful step. Thus, by means of increasing their agency, people can transcend the structure of their daily life.

Another aspect which might explain why some people change their lives might be that in the Western World, development is an important value. Giddens argues that the self in modernity is seen as autonomous and integrated into an ethos of personal growth (in: Hay et al. 1997: 88). This view is related to capitalism, in which achievement and growth are highly valued. King et al. stress that “the most important aspect of living is achieving self-understanding or a new set of beliefs or values that guide our lives” (2003: 194). Frank adds that in the Western World, self-change has become commercialized, dogmatized, and trivialized (1993: 48). Whether trivialized or idealized, cultural context could stimulate some people to change. This argument, however, does not explain why other people do *not* transform. Factors such as social support, work, and spirituality might help some people transform, but the weight of these factors is different for each individual. In addition to these factors, a person’s character, approach to life, and education might also play an important role. In summary, there are many aspects which could explain why some people do and some do not experience posttraumatic growth. To find an answer to this question requires profound further research.

Conclusion

In this article I called attention to the phenomenon of posttraumatic growth and Adversity-Activated-Development. I criticized the negative bias which prevails in the literature and public opinion about chronic illness and disability. Chronic illness is not necessarily an entirely negative experience. Being confronted with chronic illness and disability can offer people the possibility to transform their lives. Since people who experience personal growth have reflected well about their situation and also report to have difficulties with their condition, I argue that their experience is not merely a coping mechanism or illusion.

Posttraumatic growth and Adversity-Activated-Development are concepts that leave many questions open. An important one, which I address in this article, but which is difficult to answer, is why some people experience positive development, while others keep struggling with their illness. Although applying the concept of liminality does not offer an entirely satisfying answer or explication, it shows that reflection might be an important condition which could determine why some people are able to transform their illness experience. Furthermore giving meaning to one’s suffering and a person’s agency might contribute to a positive illness experience. Other protective factors like the support of family and friends, employment, and spirituality

might also positively shape the experience. Yet, these factors seem to differ for every individual in their impact and importance. As many questions are still left open, more (anthropological) research should be done in this field.

Finally, I do not want to create the impression that living with a chronic and progressive illness is easy: being confronted with an incurable and progressive illness can be very hard. Yet, I want to call attention to the fact that many people, who in my eyes are underrepresented in the literature about chronic illness, are able to deal well with their situation or even experience personal growth. This is important, not only for scientists, health care workers and clinicians, but also for family, friends and work colleagues; in short for everybody who is in contact with somebody who has a chronic illness or disability.

Notes

The author recently graduated in cultural anthropology at the University of Amsterdam. This article is based on her Master thesis (Hoppe 2009). She is grateful for the feedback and comments that helped her to improve this article. E-mail: silkehoppe@gmail.com.

- 1 Multiple Sclerosis is a chronic illness of the nervous system, which leads to the loss of bodily functions and leaves permanent changes (Kralik et al. 2006: 187). The main symptoms are numbness, problems with coordination, balance and speech, stiffness, incontinence, and muscle weakness. The exact cause of Multiple Sclerosis is unknown, the prognosis is unpredictable, and there is no effective treatment.
To assure anonymity I used pseudonyms for my informants.
- 2 Ireland only has about twelve neurologists for a population of almost 4.5 million.
- 3 I have to add that because of the restriction of my fieldwork period I cannot say much about the stability of the experience of personal growth of my informants. The narratives I analyzed are only a snapshot; how people experience their illness in the future can change completely. Moreover for each person, multiple versions of an illness narrative exist (Hydén 1997: 52).

References

- Albrecht, G.L. & P.J. Devlieger
1999 The disability paradox: High quality of life against all odds. *Social Science & Medicine* 48: 977-88.
- Boyd, E.M. & A.W. Fales
1983 Reflective learning: Key to learning from experience. *Journal of Humanistic Psychology* 23 (2): 99-117.
- Bury, M.
1982 Chronic illness as biographical disruption. *Sociology of Health & Illness* 4: 167-82.
1991 The sociology of chronic illness: A review of research and prospects. *Sociology of Health & Illness* 13 (4): 451-68.
- Canda, E.R.
1988 Therapeutic transformation in ritual, therapy, and human development. *Journal of Religion & Health* 27 (3): 205-20.

- Charmaz, K.
 1983 Loss of self: A fundamental form of suffering in the chronically ill. *Sociology of Health & Illness* 5 (2): 168-95.
 1991 *Good days, bad days. The self in chronic illness and time*. New Brunswick: Rutgers University Press.
 1995 The body, identity, and self. Adapting to impairment. *The Sociological Quarterly* 36 (4): 657-80.
- Chiu, L.
 2000 Transcending breast cancer, transcending death: A Taiwanese population. *Nursing Science Quarterly* 13 (1): 64-72.
- Cokerham, W.C.
 2005 Health lifestyle theory and the convergence of agency and structure. *Journal of Health & Social Behavior* 46 (1): 51-67.
- Egnew, T.R.
 2005 The meaning of healing: Transcending suffering. *Annals of Family Medicine* 3 (3): 255-62.
- Emirbayer, M. & A. Mische
 1998 What is agency? *The American Journal of Sociology* 103 (4): 962-1023.
- Frank, A.
 1995 *The wounded storyteller*. Chicago: University of Chicago Press.
- Giddens, A.
 1984 *The constitution of society: Outline of a theory of structuration*. Cambridge: Polity Press.
- Hallstein, A.L.
 1992 Spiritual opportunities in the liminal rites of hospitalization. *Journal of Religion & Health* 31 (3): 247-54.
- Hay, C., M. O'Brian & S. Penna
 1997 Giddens, modernity and self-identity: The 'hollowing out' of social theory. In: G.A. Byrant & D. Jary (eds.), *Anthony Giddens: Critical assessments*. London: Routledge, pp. 85-112.
- Hoppe, S.
 2009 "Multiple Sclerosis was definitely a life-changing event for me." Chronic illness as a transformative experience. Master thesis, University of Amsterdam.
- Hydén, L.-C.
 1997 Illness and narrative. *Sociology of Health & Illness* 19 (1): 48-69.
- Jacoby, A. et al.
 2005 Epilepsy and social identity: The stigma of a chronic neurological disorder. *The Lancet Neurology* 4 (3): 171-78.
- Kapferer, B.
 1984 Introduction: Ritual process and the transformation. In: B. Kapferer (ed.), *The power of ritual: Transition, transformation and transcendence in ritual practice*. Adelaide: Department of Anthropology [1979].
- King, G. et al.
 2003 Turning points and protective processes in the lives of people with chronic disabilities. *Qualitative Health Research* 13 (2): 184-206.
- Kirmayer, L.J.
 1994 Improvisation and authority in illness meaning. *Culture, Medicine & Psychiatry* 18: 183-214.

- Kralik, D. et al.
 2006 Resilience in the chronic illness experience. *Educational Action Research* 14 (2): 187-201.
- Little, M. et al.
 1998 Liminality: A major category of the experience of cancer illness. *Social Science & Medicine* 47 (10): 1485-94.
- Luthar, S.S. et al.
 2000 The construct of resilience: A critical evaluation and guideline for future work. *Child Development* 71 (3): 543-62.
- Lynch, S.G. et al.
 2001 The relationship between disability and depression in multiple sclerosis: The role of uncertainty, coping, and hope. *Multiple Sclerosis* 17: 411-16.
- Murphy, R.F. et al.
 1988 Physical disability and social liminality. A study in the rituals of adversity. *Social Science & Medicine* 26 (2): 235-42.
- Navon, L. & A. Morag
 2004 Liminality as biographical disruption: Unclassifiability following hormonal therapy for advanced cancer. *Social Science & Medicine* 58: 2337-47.
- Papadopoulos, R.
 2007 Refugees, trauma and Adversity-Activated Development. *European Journal of Psychotherapy & Counselling* 9 (3): 301-12.
- Robinson, I.
 1988 *Multiple Sclerosis*. London: Routledge.
- Schouten, J.W.
 1991 Selves in transition: Symbolic consumption in personal rites of passage and identity reconstruction. *Journal of Consumer Research* 17 (4): 412-25.
- Stark, S.
 1994 A nurse tutor's experience of personal and professional growth through action research. *Journal of Advanced Nursing* 19: 579-84.
- Susman, J.
 1994 Disability, stigma and deviance. *Social Science & Medicine* 38 (1): 15-22.
- Taylor, S.E. & D.A. Armor
 1996 Positive illusions and coping with adversity. *Journal of Personality* 64: 4.
- Taylor, S.E. et al.
 2000 Psychological resources, positive illusions, and health. *American Psychologist* 55 (1): 99-109.
- Tedeschi, R.G. & L.G. Calhoun
 2004 Posttraumatic growth: Conceptual foundations and empirical evidence. *Psychological Inquiry* 15 (1): 1-18.
- Tedeschi, R.G. et al.
 1998 Posttraumatic growth: Conceptual issues. In: Irving B. Weiner (ed.) *Personality and Clinical Psychology Series*. Mahway: Lawrence Erlbaum Associates, pp. 1-22.
- Thompson, A.J. & J.C. Hobart
 1998 Multiple sclerosis: Assessment of disability and disability scales. *Journal of Neurology* 245 (4): 189-96.
- Thorne, S. & B. Paterson
 1998 Shifting images of chronic illness. *Journal of Nursing Scholarship* 30 (2): 173-78.

- Thorpe, K. & J. Barsky
2002 Healing through self-reflection. *Journal of Advanced Nursing* 35 (5): 760-768.
- Turner, V.
1967 *The forest of symbols: Aspects of the Ndembu ritual*. Cornell UP, Ithaca, New York: Cornell University Press.
- Van Gennep, A.
1977 *The rites of passage*. London: Routledge [French original 1909].
- Ware, N.C.
1999 Toward a model of social course in chronic illness: The example of chronic fatigue syndrome. *Culture, Medicine & Psychiatry* 23: 303-31.
- Wineman, N.M.
1990 Adaptation to Multiple Sclerosis: The role of social support, functional disability, and perceived uncertainty. *Nursing Research* 39 (5): 294-99.