“Multiple Sclerosis was definitely a life-changing event for me”

Chronic Illness as a Transformative Experience

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Content

1. Prologue

It was a cold winter day when I set off to the Multiple Sclerosis (MS) care center to meet Emily, who was willing to answer some questions about her illness. Waiting for the double-decker bus in the traffic jam, I felt my excitement for my first interview in Dublin growing. I had met Emily for the first time when I introduced myself to the MS society in order to find contacts and informants for my study. Emily directly agreed to talk to me. Before our appointment, she told me that she does not think of herself as having MS. She added that she is not in denial either. As I had only seen her sitting behind the reception desk I assumed that she had a very mild form. But I was mistaken. When I came to the interview she first went to the toilet. Later I realized that she probably went because the illness has weakened her bladder. While Emily sat on her walking frame, her colleague pushed her to the library where the interview took place. Getting up from the walking frame and sitting down, she was very deliberate and moved one foot after the other. Witnessing this, I was surprised about her earlier statement, since in my eyes her illness obviously limited her in a decisive way. However, during our conversation I learned that she was trying to live as normally as possible and to not let her illness affect her life too much. Emily expressed that she leads a happy life and that after being diagnosed she has lived life more to the full. She surprises me again by stating that her MS was a ‘grace of God.’ As Emily shared more intimate information in our following conversations, I came to understand how she arrived at this point of view. For years she was unhappy with her life. Her illness was a turning point which made her change her priorities and outlook on life.

> 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. There are people like that, who don't see anything, they are just so busy, busy busy, preoccupied. 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.

Getting Multiple Sclerosis made Emily change her priorities and gain a different perception of life. She doubts that without her illness she would have changed to the same extent. Apparently she compensates for all the disadvantages that are caused by her illness by giving meaning to her illness and transforming it into a positive and salutary experience. In the course of my fieldwork I discovered that Emily was not the only person who viewed MS in a positive light. Other participants had similar experiences and underlined that by getting sick they reconsidered their outlook on life. In my view, perceiving their illness in a positive way was not the result of external circumstances, such as a tax abatement, special treatment, or more attention. People did not deny their illness either, but in contrast to other people with Multiple Sclerosis they manage to overshadow the difficulties of their disease by perceiving it in a positive way. However, I also met people who were devastated by their illness. They had difficulties going on with life and dealing with their condition.

Meeting so many different personalities who each had their own way of dealing with their illness and of expressing their experience made me wonder what would determine how people experience their illness. Therefore I shifted my research focus from analyzing how people with Multiple Sclerosis experience their body in relation to meaning and practice of the body in the Catholic Church to finding an explanation for the variety in the illness experience.

2. Introduction

2.1. Research Question

What is it like to be chronically ill? How do people experience a chronic and progressive illness, knowing that it cannot be cured and that their illness will worsen? How do people deal with everyday problems that arise from their condition? Is their illness on their mind all the time, or do they get used to it? What role do physical symptoms play in the experience of the illness? For an outsider it is hard to imagine what it is like to live with a chronic and disabling illness (Morse & Johnson 1991: 1).

In a presentation I gave for an academic audience about my research, I asked people what they would associate with a chronic and disabling illness. The answers I got were social isolation, lost mobility, wheelchairs, dependence, hospitals, and fear. Their answers, I believe, reflect a general negative bias towards chronic illness and disability. Often people immediately think of negative aspects, and do not realize that chronic illness is not an entirely bad experience for everyone. This bias probably is a result of a combination of factors. Most people do not know somebody with a disability or chronic illness; others are afraid of acquiring a disability and prefer to avoid anything that has to do with it. In addition, the media shapes the way people perceive disability and chronic illness. Often people with a disability are represented in a stereotypical manner as dependent and needy. Charity campaigns encourage audiences to pity people or children with a disability in order to solicit donations. Stories about people who positively deal with their disability only seldom appear in the media.

Another reason why few people understand the illness experience is that it is often hidden from public. Some people find it hard to talk about their illness; others do not have anybody listening to their story. In my study I want to give a voice to people suffering from Multiple Sclerosis, a chronic and disabling disease that involves the loss of bodily functions and control and which restricts a person’s daily life.[1] During my fieldwork I gathered many different voices reflecting different illness experiences. I was amazed by the complexity and variety of illness experiences. Multiple Sclerosis is often called the disease with the thousand faces as its symptoms can vary from individual to individual. But not only did everyone have different symptoms and a

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[1] I use the expression ‘suffer from Multiple Sclerosis’ as an equivalent to ‘have Multiple Sclerosis’ and do not imply by this that people suffer from their condition.

different course of the illness; everybody also differed greatly in the way they experienced Multiple Sclerosis. I met people who had to be in a wheelchair but who seemed to have adapted well to their condition. I talked to people suffering from very mild symptoms but who experience many problems and I interviewed people who expressed that their illness made them change for the better. Confronted with this variety I wondered how these differences in the illness experience could be explained. The research question this thesis aims to answer is: *How do people who have been diagnosed with Multiple Sclerosis experience their illness and how can differences in their experience be explained?* Initially I was inspired to research how people approach their illness in a positive manner. But during the process of writing, my emphasis shifted. My concern is to explain why people experience so many problems with their illness, and how they could be assisted.

In the following I introduce relevant literature about the topic of my research. I give a short definition of chronic illness and then present an overview of how chronic illness experience has been analyzed during the last decades. Further, I debate what it means for a person to suffer from a chronic and disabling illness. Similarly, I demonstrate how the body has been analyzed within social and medical anthropology and how a person's relationship to the body can change through a chronic illness. Finally I provide information about Multiple Sclerosis. This chapter ends with a presentation of the methodology I used in this research and an outline of my thesis.

2.2. Chronic Illness Experience

Chronic illness and disability can have invasive effects on a person's life. "A chronic illness is one that persists over time, usually without an easily definable beginning, middle or end" (Kralik *et al*. 2006: 187). Changes resulting from chronic illness are often permanent and ongoing (*ibid*.: 198). Chronic illness in contrast to acute illness changes the foundations of life "because the illness creates new and qualitatively different life conditions" (Hydén 1997: 52).

As more and more people in the western world suffer from chronic illness, more attention is being paid to it in the fields of medicine and sociology (Locker 2000: 77). According to Kelly and Field, illness is a "multi-phenomenal experience" (2004: 256) which can be analyzed in different layers. One can study how a chronic illness impacts a person's life, family, and community. Other fields of analysis are the way of dealing and coping with the disease or how the sick person perceives his or her body. Kelly and Field have further distinguished two paradigms within medical sociology that concern the illness experience. The first paradigm is the socio-structural approach, and the second the interactionist approach. The first approach focuses on the impact chronic illness has on an individual, their family, employment and leisure (Kelly & Field 1997: 4). Parsons (1951), who concentrated on the sick role, is one example of this approach. From his point of view, sickness interrupts normal social functioning and the accomplishment of role responsibilities (Kelly & Field 1998: 4). Scholars, who study sickness by focusing on deviation and labeling also belong to this approach. Bury is another author who writes about the impact chronic illness has on an individual. He describes it as “biographical disruption” (1982) and argues that chronic illness not only assaults the body but also the person’s sense of identity and their self-worth (Bury 1991: 453). Furthermore, he states that chronic illness disturbs the “structures of everyday life, its taken-for-granted features, and the tacit stocks of knowledge upon which they rest” (in Williams 2000: 43). These scholars apply a predominantly ‘etic’ point of view. Their focus is mainly on the impact a chronic illness has on people and their social environment.

In contrast, the interactionist approach centers predominantly on the experience of chronic illness. Meaning and adaptation play a central role. Another difference is that this approach “does not assume a priori and inevitably that chronic illness is only a negative experience” (Kelly & Field 1998: 6). Strauss and Glaser (1975) analyze the illness experience through grounded theory from the patient’s point of view. Because they paid attention to the meaning the illness has for the individual they belong to the second paradigm (in Williams 2000: 42). Similar, Charmaz depicts the experience of chronic illness in three different ways; firstly as an interruption of people’s life, secondly as an intrusion, and thirdly as an immersion (Charmaz 1991). Charmaz states that people can either experience loss or transcendence of self. According to her, people have to adapt to a changing body which leads to a change in self perception and self worth.

In a meta-study Thorne and Paterson (1998) analyze how chronic illness has been viewed and analyzed over the years. In the 1980’s researchers began focusing on the inside perspective of patients. Predominant themes were suffering (Charmaz 1983), loss (Duval 1984), biographic disruption (Bury 1982), and the sick role (Steward & Sullivan 1982). A decade later, scholars approached chronic illness in a more optimistic way. Research concentrated on themes such as courage and hope, reshaping the self, regaining control, finding meaning, empowering potential, normality, and discovery (in Thorne & Paterson 1998: 175).

However, in spite of this paradigm shift, a relatively negative attitude towards chronic illness persists. Albrecht and Devlieger criticize that “there is a decided negative bias in the attitudes and expectations of the public and health care workers towards persons with disabilities

(Wright, 1988)" (1999: 978). Moreover, scholars analyzing chronic illness mostly generalize the experience of chronic illness. Bury (1982) assumes that chronic illness for everybody is a 'biographical disruption' and Charmaz (1991) only describes different stages of the intrusion of chronic illness. What is absent is a more specific and at the same time broader framework which not only provides one category of illness experience, but accounts for different forms. During my fieldwork I came across a variety of ways of experiencing and narrating chronic illness which I present in the next chapter. As Kleinman & Kleinman point out it is important to focus on what is at stake for a person suffering from an illness (1991: 277). Hence in the following section I will discuss what it means for a person to be diagnosed with a chronic and debilitating illness and how people deal with it.

Kleinman compares having a chronic illness to a volcano in that firstly, it does not go away and secondly it menaces, erupts and is out of control. Living with a chronic illness further involves the loss of trust in one's health and bodily functions (Kleinman 1988: 45). Kleinman shows how "illness becomes embodied in particular life trajectory [soaking] up personal and social significance from the world of the sick person" (in Garro 1994: 775). Hence people suffering from a chronic and progressive illness are faced with uncertainty and fear. As the years pass some people get used to their condition and are better able to deal with it. Yet, since the illness progresses people constantly have to confront new challenges that result from their illness. People over the years change their strategies of dealing with their illness. While they first might have decided to hide it, they might at a lager stage reveal and speak openly about it.

Living with a chronic illness means that small things like not being able to take out the trash can evoke existential dilemmas. People question their self-worth and wonder about the sense in living (Charmaz 1991: 135, 137). In order to organize their lives people make new priorities depending on what they are still able to do. "They simplify their lives, reorder their time, and juggle and pace their activities to fit their lives" (*ibid*.: 143). The way people experience those changes and the impact of the illness varies for every individual. As the body plays a crucial role in the experience of one's condition, in the following I will discuss the role and importance of the body in chronic illness and disability.

2.3. Anthropology of the Sick Body

> The body is more than just an object to be decorated and enhanced. It is more than a physiologic organism functioning according to a prescribed genetic code. It is more than a container of the self. It is more than a mediator between the self and the world. It is, as Merleau Ponty (1962) states, the embodiment of who we are. The self becomes what it is through body. The body is the self's representative in the world (Corbin 2003: 258).

In anthropology it is acknowledged that the way a person experiences and perceives the body depends on a social and cultural context. Social scientists have noted that the body through history has been interpreted, perceived and represented differently (Lupton 1994: 21). The body is a product of the socio-cultural and historic context (Lock 1993: 134). Instead of as passive object of study, the body is approached as an agentive entity, which is not subordinated to structure but which plays out individual agency. In spite of the increased interest in the body, little research focuses on the moving body. Thus, although social scientists acknowledge that the body is a socio-cultural entity, it is still seen as a rather static object of study which is separate from the mind. In ethnographic theory the body therefore should more be approached as a moving agent (Farnell 1999: 348).

Taylor, among others, works out the famous statement of Merleau-Ponty that 'we all have and we all are a body' and adds that "bodies are also something that we do and do in multiple ways" (Taylor 2005: 745). By focusing not only on the body but also on the moving body, social scientists can analyze how the body is enacted differently in diverse settings and thereby gain more sophisticated insights into the body. Certain disease like Multiple Sclerosis, which I will discuss in the following sections are, depending on the severity of the illness, only visible to outsiders when the sick person is moving. Moreover, a person can enact his body differently in various situations, such as the hospital, at home, or at work. Whereas in the hospital bodily weaknesses and problems might be more emphasized, they might fade into the background at work where people want to present themselves as strong and capable.

The body can be analyzed in different ways. Douglas distinguishes between a natural and a social body. According to her, the perception of the physical body is shaped by the social body (Douglas 1970: 65). Douglas emphasizes that we cannot treat the individual body in isolation but have to be aware of the social and cultural context surrounding it. Scheper-Hughes and Lock (1987) further developed this concept of the body. They conceptually divided the body into three bodies (the individual body, the social body, and the body politic) which also represent different anthropological approaches. Furthermore they replaced the natural body with the individual body, an approach which offers the advantage that the body is not automatically seen as natural. According to Scheper-Hughes and Lock the individual body centers on the experience of the body and the way we see our body. The social body refers to the body as a symbolic representation of the world (see Douglas 1970) and an embodiment of it (see Bourdieu 1977). The body politic refers to the control and regulation of the body through power (Scheper-Hughes & Lock 1987: 7).

With the emergence of medical anthropology, researchers developed more concepts and ideas about the sick body. As the disability movement advocated the rights of people with a disability and argued that scientists understated the important role bodily difficulties play in the experience of disability and illness, during the last two decades the sick body gained a more central role (Kelly & Field 2004: 258; Lupton 1994; Lock 1993). Chronic illness and disability occur in the body, and the body is changed by chronic illness. The self-conception of the body changes as well, as it is connected to the experience of the body, feelings and actions (Kelly & Field 2004: 258).

Focusing on the sick body can give insight into how sickness can lead to changes in the three bodies discussed by Scheper-Hughes and Lock (1987). Sickness and the loss of bodily functions can result in different experiences and perceptions of the body. Sickness can work as a symbol through which society perceives an individual. When a disease is visible people suffering from it can encounter stigmatization. That means the person is reduced to the impairment, which overshadows his or her actual social identity (Goffman 1963: 3). Moreover, the person with an illness can adapt a sick role (Parsons 1951) which is imbedded in a social and cultural context. A disease can be seen in moral terms, as a consequence of or even punishment for bad behavior (Lupton 1994: 90). Although the individual is not responsible for a disease, society can treat the person as if he were. How a disease is perceived and experienced by sick individuals can also be shaped by the way medical scientists or insurance companies treat the disease.

Being sick can mean that the body is subject to the control and regulations of the medical system. Foucault deconstructed the way the body is controlled through institutions, such as hospitals or prisons. He argues that the mind has been controlled and addressed through the body. Foucault states that, with the rise of the modern capitalist society, different institutions developed new forms of power and knowledge in order to control the body (Foucault, in Schepher-Hughes & Lock 1987: 26). In psychiatry and medicine, more strict definitions of ‘normal’ and ‘sick’ or ‘deviant’ were increasingly used. Medicalization is one example of how human distress and the body have become more controlled.

But what is the role of the body in the experience of a chronic and progressive illness? “Chronic illness assaults the body and threatens the integrity of self. Having a serious chronic illness shakes earlier, taken-for-granted assumptions about possessing a smoothly functioning body” (Charmaz 1995: 657). People suffering from Multiple Sclerosis have to adapt to a changing body and loss of function in an ongoing process. As a physical illness obliges more awareness of the body as being distinct from the self (Garro 1994: 782), people may feel alienated from their body. Alienation is expressed when people say ‘the leg’ instead of using the expression ‘my leg’. Another characteristic of alienation is that people have the impression that they cannot trust their body anymore (Charmaz 1995: 662) and feel let down by it (Robinson 1988: 42). However, people might also come closer to their body as they learn to listen to it and begin to appreciate it. “The ill person may feel that he or she is beginning to unify the altered body and the self” (Charmaz 1995: 664). In the following chapter I demonstrate how the experience of the illness is connected to the experience of the body. I argue that the body can be used to help determine how a person experiences his or her illness. Prior to this discussion, however, I provide more detailed information about Multiple Sclerosis.

2.4. Multiple Sclerosis

Multiple Sclerosis is a disease of the nervous system which leads to the loss of bodily functions. The main symptoms are numbness, problems with coordination, balance and speech, pain, stiffness, incontinence, and muscle weakness. Neuropsychological problems like lack of concentration, oblivion, and disturbed self-perception can also result from Multiple Sclerosis. It is a progressive disease thus the symptoms often worsen over the years but do not affect longevity (Thompson & Hobart 1998: 190). The exact cause of Multiple Sclerosis is unknown, the prognosis is unpredictable and there is no effective treatment (Robinson 1988: 1). Multiple Sclerosis mostly affects “young adults at a crucial stage in their lives when they are establishing their careers, setting up home and having a family” (Thompson & Hobart 1998: 190).

There are four types of Multiple Sclerosis: relapsing remitting, secondary progressive, primary progressive and progressive relapsing. Relapsing remitting is the type most individuals have first. It involves unpredictable relapses, which can leave permanent impairments. Those relapses are followed by a period of remission. The second type, secondary progressive, can be a sequence of the first type. The illness progresses continuously, without any attacks or periods of remission. The other two subtypes are not very common. People who are diagnosed with primary progressive Multiple Sclerosis do not have a remission after their first symptoms. They experience a progression of the illness without attacks. The last type, progressive relapsing, means that people experience a steady deterioration but also have attacks.

Suffering from Multiple Sclerosis can have far-reaching consequences. Individuals may encounter problems in the accomplishment of daily tasks. They may be unable to work, impacting their financial situation, their social status, and social network. People may have to deal with unemployment, sexual dysfunction, divorce, depression or even suicide (Thompson & Hobart 1998: 190, Duval 1984: 663). Another problem which can occur in the course of the disease is that people become more and more dependent. They may have to rely on the help of a partner, medical staff, or on a larger scale on financial support of the state.

On the one hand receiving a diagnosis can be stressful (Duval 1984: 636). Yet, on the other hand the diagnosis is important to patients as it gives them an explanation for their symptoms and a legitimization for their behavior (Robinson 1988: 29). Being officially diagnosed, they can account for shortcomings which are a result of their illness. Research demonstrates that there can be four different stages of reacting to the diagnosis. First people are in denial, secondly they resist the illness, thirdly they confirm it, and finally they try to integrate it into their lives. This is not a linear process; rather the different reactions can occur simultaneously or overlap each other (i*bid.*: 32). According to Robinson three strategies of dealing with the condition exist. First people can apply the strategy of passing. “Passing can be described as the strategy of passing oneself off as not having a disease or disability by attempting to maintain its social invisibility” (*ibid.*: 51). The second strategy is normalization whereby people strive to live as normally as possible. The illness forms part of their lives but not a dominant one. The third strategy is disassociation. Hereby people create a new lifestyle which is adjusted to a different reference group. One’s behavior is not compared with the normal social environment, but with people who have the same disease (*ibid.*). Interacting with other people with a disability has the advantage of creating a more positive attitude towards their fellow suffers and a better understanding of their own problems. “These attitudes were expressed in terms of willingness to interact with and feel empathy for persons with disabilities” (Albrecht & Devlieger 1999: 978).

How people experience their illness differs from individual to individual. It is important to note that the “*personal interpretation* of events, rather than the events themselves” is significant in determining the illness experience (Robinson 1988: 32). Thus, the relationship between the subjective illness experience and the physical symptoms is very complex. Furthermore, cultural context can shape the way people experience their condition. The situation in Ireland with regards to disability and chronic illness differs from the situation in mainland Europe. In contrast to the Netherlands where the disability movement took place in the sixties and seventies, in Ireland this movement only happened during the last decade. Therefore the rights of people with a disability only recently began to be recognized. Many health care services still have to be improved. There is not enough money for services like adapting the house for someone with a disability or for providing them with aids. Much help still relies on charity. Therefore people are more dependent on the help of friends and family or on a charity organization. Ireland has only twelve neurologists for its entire population. In consequence patients might have to wait for a long time until they can consult a neurologist. Having to wait for a diagnosis for many month or even years, not receiving any medical treatment, and not knowing what is going on can be very stressful and increase the problems people experience with their condition.

My informants told me that discussing illness and other personal issues in Ireland still is rather taboo, especially in the older generations. Ireland has been a relatively homogenous population, in which the largest dissimilarities were about being Catholic or Protestant. Therefore, as some informants told me, a general tendency to avoid sensitive issues exists. As a consequence people do not ask many questions when they see somebody with a disability. Often they do not know how to behave, which is rather out of ignorance than out of bad intentions. Not being able to talk about one’s condition can lead to an increased feeling of isolation. In the preceding sections I introduced central concepts of my research. Now I discuss how I investigated these concepts.

2.5. Methodology

This thesis is based on research using qualitative research methods. My fieldwork took place in Dublin, where I stayed from the 10th of December 2008 till the 6th of April 2009. In order to find participants for my study I contacted the Irish MS society.[2] Social workers of different regional offices helped me contact people who have Multiple Sclerosis. One third of my informants were directly asked by a social worker to participate. Almost two third reacted to a letter I wrote, which was spread at a Yoga and information meeting. A few informants were introduced to me via other participants. In the course of my fieldwork I interviewed twenty persons who all live in Dublin. Their age ranged from twenty-four to seventy-six years; half of them were men, and half of them were women. My informants belong to various social classes, ranging from upper class to working class. They have different forms of Multiple Sclerosis and different grades of disability. About half of my informants had relapsing remitting MS, the other half secondary progressive MS. One third of my participants were in a wheelchair, another third were using a stick, and the last third was moving around without any walking aid. The symptoms of my informants included fatigue, blurred vision, balance problems, pain and stiffness, muscle weakness, mental problems, and incontinence. The majority of my informants were still living independently, though a few had people who took care of them and one was living in a nursing home. Half of them were still working, the other half were either early retired or on a pension. In general my informants have rather benign forms of the illness, in comparison to more aggressive, fast-progressing forms.

In addition to the twenty people with Multiple Sclerosis I also talked to some of their family members, a nurse at the MS Care Centre who regularly meets people with Multiple Sclerosis, one neurologist, people who are active in a disability organization, and a chaplain who counsels people with a severe illness. By talking to other people I gained a broader picture of the situation in Ireland. Talking to family members gave interesting insights into the discrepancy between the patient's experience and the family member's impressions. By asking the same questions to somebody with Multiple Sclerosis and a healthy person, I could better judge whether the answer was illness-specific.

Half of my core informants I met once, the other half I met two or three times over a period of time. Thereby I was able to build up a relationship of trust, which often led to more intimate and deeper conversations. As illness narratives, which I analyze in my study, are situational and dependent on context (Hydén 1997: 52), talking to informants over a period of time, gave me a better evaluation of my participants and of the stability of their experience. This also gave informants the possibility to reflect on our last conversation, as they did not think earlier about some issues I addressed. But as one participant said, any interview is simply a snapshot; how people experience their illness in the future can change completely.

For each person, multiple versions of an illness narrative exist (*ibid.*). As Charmaz describes, people experience good days and bad days (1991). One day they consider their illness a terrible experience and on another day they are able to deal with it well. Therefore in my research I do not present one 'true' illness narrative, but illustrate how people narrate their illness. If I met

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[2] http://www.ms-society.ie/

people more than once I compared their narratives and analyzed which elements remained the same and which were different. It was important for me to meet people in their natural environment where they feel comfortable, because the context shapes the way people narrate their illness (Hydén 1997: 62). Hence I provide a short introduction of the context in which the interview took place. While I met about half of my informants at their home, the other half I met at their work, in pubs, cafes or restaurants. Seeing people at their home had the advantage that I could observe to what extent they could still live independently and move around. Meeting people in public spaces on the other hand gave me more insight in how people reacted to them and how they dealt with that.

The interviews all took at least one hour; some lasted for three hours. They ranged from informal conversations to formal interviews. In the interviews I had a list of questions and key issued that I wanted to address and which I adjusted to each individual. I gave them enough room to express what they found important and to go into detail where they wanted to. During the interviews I paid attention to body language, gestures and changes in my informant's voice. I transcribed all interviews and took notes during or after the conversations that were not recorded. In total I gathered sixty-five hours of audio material. I read through the interviews several times and coded the important passages. As some informants wanted to remain anonymous I used pseudonyms.

During the fieldwork I applied triangulation to increase the validity of my research. First I talked to the majority of people more than once, and second I applied participant observation to check whether what people said was concordant with what they did. By observing their behavior I could see whether people would for example ask for help, or whether they preferred to do everything by themselves. Their outward appearance (whether they appeared well cared for or not) revealed something about their situation. Through observation I assessed their physical limitations and compared them to my informants' descriptions.

In the analysis of the data I used the grounded theory approach. My theory is based on the data I collected. I believe that knowledge is created in interaction and that information is communicated via different means, such as speech, body language, gestures and clothing (Price 1999: 4). My approach could also be described as phenomenological as I study the lived experience of people (*ibid.*: 3). My thesis contains the interpretation of people's illness narratives and transformations. In my analysis of people's stories I also "[l]ook at the spots where it 'irritates' (Prokop, 1996) – where something 'does not fit' or seems to be missing, where the text becomes contradictory or maybe too coherent, where the rhetoric is experienced as ambiguous, touching, or untrustworthy" (Nielsen 1999: 51). Hence I also analyze things that have not been said.

2.6. Research ‘at home’

“Developing a qualitative study positions the author as artist, interpreter, and composer” (Price 1999: 1). How the researcher is related to the topic and the people he is studying shapes the whole research. Riessman underscores the importance of the researcher’s social position, subjectivity and interpretation. She argues that the “[i]nvestigator positioning is important because it shapes the production of knowledge” (Riessman 2003: 6). Listening to an illness narrative of a person also means taking an active part in its construction (Hydén 1997: 60). In the following I will outline my own background in order to clarify my impact on the study.

As I also have a chronic and disabling illness similar to Multiple Sclerosis, I was especially interested in this topic. One reason of doing this study was to give voice to people having a chronic illness. From my own experience people had an either too negative or too positive picture of living with a chronic illness. By talking to people who are living with a chronic and disabling illness I wanted to contribute to a better understanding of what it is like to live with such an illness. I used my own illness as a way to get access to my participants. However as some informants were contacted via a third person, for example a social worker of the MS society, not every participant knew of my background.

Depending on the situation, I made mention of my own condition, but only if people directly asked me or at the end of our conversation. I had the impression that some informants talked more openly with me, because they felt more comfortable around somebody with a similar condition. One informant gave me the feedback that he was very happy to talk to somebody who shares a likewise fate. Another person said that he was glad that I did not tell him of my background because in his opinion Irish people would then assume that you already know everything. When people asked me about my opinion on certain issues it was already after they had given an answer to that question. In that way my replies did not affect their answers.

Although my research did not take place in my native country, my research can be assigned to the field of doing anthropology at home. Whereas anthropology started as a discipline studying distant and ‘exotic’ groups, doing anthropology at home has become more common (Peirano 1998: 105). Following the argument of Reis, I define being at home not as referring to a geographical place but to shared experiences (1998: 295). Reis points out that affective resonance and introspection can be used as tools to analyze one’s data (*ibid*.: 307). Likewise, Lillrank places emphasis on the utility of emotions. “Only when the emotional dimensions of research interview interaction are acknowledged and discussed can the true meaning of the obtained data be understood and appreciated” (2002: 123-124). The interviews I conducted touched upon sensitive topics. Varying from individual to individual the conversations were emotionally charged. My informants’ stories affected me emotionally as some informants apparently struggled with their situation but also because they confronted me with my own story. Painful experiences I shared with some informants are the shock of being diagnosed with an incurable and progressive disease, the feeling of being isolated with the illness and having nobody to talk to and initially being ashamed of my disability. Realizing that people, strangers but also friends and family, are not always considerate of my disability is another hurtful experience I made and recognized in some of my informants. Other aspects I had in common with some informants were the fear of the future and the realization that there are more and more things I cannot do and will not be able to do. Having to ask people for help and depending on others was another difficult lesson to learn. For many years I pretended to be fine and in control of the situation, although I was not. I had the impression some informants behaved in the same way.

I used my emotions as a means to add information to my analysis and to give it more depth. Sometimes people narrated their story in a neutral way and emphasized that they master their illness. Yet after some of those interviews I felt depressed. I believe that this was a result of what Lillrank names ‘covert emotions’. She argues that some aspects of an illness are too painful to talk about and therefore remain unsaid. But only when ‘overt talk’ and ‘covert emotions’ are taken into account the depth of suffering from an illness can be understood (Lillrank 2002: 111). Thus when I felt emotionally affected I analyzed to what extent this had something to do with me and to what extent with the other person. I argue that because I made similar experiences I was able to recognize some emotions of my informants although they did not directly express them. Somebody who might not have a similar background might interpret the respondents’ narratives in a different ways. Yet, I believe in the principal points another researcher would have come to the same conclusions. Through introspection, thus analyzing to what extent and why I emotionally react to people’s stories, I have tried to give my interpretations more steadiness.

2.7. Outline

In the first chapter I present different forms of narrating the illness experience of Multiple Sclerosis. I first discuss the importance of narratives in the illness experience and how narratives should be approached. I use the illness narratives in order to come close to the illness experience of people. Analyzing the interviews with my participants, three categories of illness narratives emerged. The first category, to which about half of my informants belong, is called 'normalization' and is subdivided into two subcategories. The first subcategory refers to normalization with regards to a person's old reference group and the second subcategory, which is called disassociation, refers to normalization with regards to a new reference group. The first subcategory contains narratives in which the illness forms part of a person's life, but not a dominant one. People try to live as normally as possible. They have accepted that they have Multiple Sclerosis and although they experience different problems with their illness in general they still have a positive outlook on life. The other subcategory concerns narratives of people who disassociate themselves from their old social network and spend more time with people who have the same or a similar condition. Among those people, illness becomes something normal. The second category of illness narratives is called 'loss' and contains people who experience many difficulties and worries with their illness. Often they feel alienated from their social environment. The third category, called 'posttraumatic growth' includes illness narratives describing a positive development. People belonging to this category experience personal growth and are able to deal with their situation well. A typical statement is that people changed their priorities because of their illness, and for example now spend more time with their family. What these people have in common is that they see positive aspects in their illness and therefore experience fewer problems with it.

In the following chapter I search for factors that could explain the differences in the illness experience. The central question is why some people experience their illness as a negative interruption and others see it as an incident they used to change their lives positively. This matter is also addressed in the context of resilience theory, which I will discuss in the chapter. A factor shaping the illness experience can for example be the social network of a person. To what extent is it important that a person experiences support from the social environment? And how important is it whether people are still able to work or not? Other factors are more directly tied to illness, such as the severity of the symptoms, the visibility of the condition or the time of the diagnosis. Do people whose illness has further progressed experience more problems? What role do the visibility of symptoms and the duration of the condition play? Is it important that people give meaning to their illness through religion or spirituality? I end this chapter with a discussion of all these factors and the degree to which they help us understand and explain the differences in the illness experience.

In the next chapter I use another framework to analyze the different narratives of the illness experience. As all informants describe a transformation, either a negative or a positive one, I use the concept of *rite de passage* and liminality in order to deconstruct the illness experience. I argue that people who remain in a liminal phase experience more problems than people who are able to leave this phase. Being in a liminal phase means that people are torn between two worlds. Often they cannot keep up with their old friends but have not found new ones yet. They experience a loss of status and their social position is ambiguous. They might experience a dissolving of their gender, e.g. feeling less like a woman or man because of their disability. Decreased self-esteem is another characteristic of this phase. People who leave liminality, however, transcend these problems. Based on empirical examples, I present different ways of leaving liminality. I state that people can leave this phase by either entering into a disability culture, striving for normalization or by growing from the situation. In the following I address why some people are able to leave the liminal phase and while others still reside in it. I conclude this chapter with a discussion on the importance of rituals and ceremonies in helping people to deal with their condition. I end my thesis with a reflection and a conclusion in which I summarize my findings and discuss the implications of this study.

3. Experiencing Multiple Sclerosis

3.1. Illness Narratives

In this chapter I present different ways of experiencing Multiple Sclerosis. Since my fieldwork period was relatively short and I met people only for a brief period of time, I found the illness narrative a useful tool, when combined with triangulation, for overcoming the difficulties of discovering how people experience their illness. Thus, by gathering their narratives, meeting people more than once, observing their behavior, speaking with family members, using introspection, and deploying the concept of resonance, I try to come as close as possible to their experience.

As "[p]ersonal narrative simultaneously is born out of experience and gives shape to experience" (Ochs & Capps 1996: 20), illness experience can be studied through illness narratives. Historically, illness narratives received different amounts of attention. Before the development of the bio-medical model of illness, the doctor paid a lot of attention to the patient's story and experience. As medical technology and expertise were absent it was crucial to gather as much information as possible from the patient. A close relationship between the physician and the patient was endorsed (Porter 1997: 10). But with the growth of the bio-medical sector the patient's voice disappeared and what counted was the doctor's expertise. Medical research and testing replaced the patient's illness narrative. Doctors treated the patient's reports with skepticism (Hydén 1997: 48). However, since the bio-medical model has been criticized and holistic medicine has received increased appreciation, the patient's perspective has gained renewed attention (Bury 2001: 267).

Early social scientists studying narratives saw them as a form of representation of one's experience (Somers 1994: 606). Their main interest laid in the knowledge that was gathered. It was acknowledged that narratives were a way to create and give meaning to social reality. More recent conceptions of narratives, however, focus more on the way "*how* people talk about and present events – and not only on *what* is said" (*ibid.*). Thus, the form of the narrative and how it is presented and organized shapes the message that should be conveyed (*ibid.*). Illness narratives, on the one hand, can reveal a person's experiences and how he or she deals with the illness. On the other hand, illness narratives can illustrate the link between identity, experience, and the cultural context of a person (Bury 2001: 264). Illness narratives are the "main form through which we perceive, experience, and judge our actions and the course and values of our lives" (Hydén 1997: 49). Such narratives are often associated with change (*ibid*.: 50).

Illness narratives do not simply reflect the illness experience. First, personal narratives are always told from the present but often are about events or experiences of the past (Ochs & Capps 1996: 25). Hence, they are remembered and as Bartlett (1932) stated remembering is rather constructive than simply reproductive (Mattingly & Garro 2000: 70). Information and emotions can be distorted, disregarded or overemphasized. When people talk about their illness experience they rely on their 'autobiographical memory'. Past events are not reproduced, but reconstructed in such a way that the present is explained and makes sense (Garro 1994: 776). Second, narratives involve a listener and thus an audience, who shape the construction of the narrative. In line with Goffman, illness narratives can be described as a performance. "What talkers undertake to do is not to provide information to a recipient but to present dramas to an audience" (Riessman 2003: 7). The illness experience is not only reflected in speech, but also demonstrated in gestures and actions (*ibid*.: 6).

Illness narratives do not present a simple truth, but are a consciously or unconsciously chosen version of a story. They mainly consist of what the narrator thinks is worth talking about (Garro 1994: 785). "Illness narratives do not reveal an essential self as much as the preferred one, selected from the multiplicity of selves or persona that we all switch between as we go about our lives (Harre & van Langenhove 1999, Riessman 2002)" (Riessman 2003: 8). In other words narratives are versions of reality; they are embodiments of the narrator's point of view (Ochs & Capps 1996: 24).

Narratives do not only make the point of view of the talker clearer, but also allow the talker to present him- or herself in a certain way. The person can showcase himself in a positive light or even as hero battling against adverse circumstances, and thus make his situation more bearable. Although narratives strive toward homogeneity, they are mostly heterogeneous (Nielsen 1999: 50). Certain aspects might be left out because they are too painful for the person to narrate. Frank terms these narratives as 'chaos narratives' and states that they are told in silence because they lie beyond speech (1995: 104). It is therefore important to reflect on the things which have not been said and to take 'covert emotions' (Lillrank 2002: 113) into consideration when analyzing illness narratives. In addition, illness narratives are dependent on context. An illness narrative is "deeply embedded within various institutional structures that influence its production as a story" (Saris 1995: 39). One can talk of a 'customization' of the illness, as narrators influenced by different sources make the illness their own (Early 1984, in Hydén 1997: 53).

Robinson presents three different forms of illness narratives. He distinguishes narratives which have stable, regressive or progressive qualities (Robinson 1990: 1176). Robinson suggests that ‘stable narratives’ connect a sequence of events without drama. Personal goals are not at the forefront of the account. In regressive narratives there is a discrepancy between valued personal aims and the possibility of their achievement. In contrast, progressive narratives describe the individual in a more positive light; their “essence is that of a positive construction of (putatively negative) events and experiences” (*ibid*.: 1178). Frank states that “illness narratives invoke change, based on understanding illness as a moment at which change is especially possible” (1993: 41). According to him every illness narrative contains an epiphany; an experience which leaves a mark on people’s lives (Denzin 1989: 70, in Frank 1993: 41). Illness narratives differ in that some stress turning points and changes, while others accentuate continuity.

In this chapter I distinguish three different illness narratives, which to some extent are in line with Robinson’s classification. These different narratives emerged through analyzing the interviews I had with my informants. The first category of illness narratives is of people who describe normalization with regards to an old or new social network; the second of narratives of people who are isolated from society and experience many difficulties, and the third is of narratives of people who experience posttraumatic growth, a concept I shall explain in the following. While narratives of the first category are characterized by stability and continuity, narratives of the second category are regressive while those of the third category are progressive. These categories have vague boundaries; some narratives show characteristics of two categories, or reside at the boundary between two categories. My categorization is only valid for a given moment in time. As illness narratives and illness experiences only are a construction, how people experience their illness can change at any moment of time and is shaped by internal and external events. .

Those three narratives are also related to different coping strategies. Coping can be defined “as constantly changing cognitive and behavior efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person” (Lazarus & Folkman 1984: 141). According to the model of Lazarus and Folkman two processes take place after a stressful event. First, the person appraises the situation and judges whether his or her resources are adequate. Second, the person tries to cope with the situation by using certain thoughts or types of behavior. Coping is mainly split into emotion-focused and problem-focused coping. The first controls affective and internal components while the latter aims at managing external aspects of the problem (in Bombardier *et al*. 1990: 297). Because of the short fieldwork period and since I am not educated as a psychologist, I cannot determine which coping strategies people use, but this model helps to elucidate why people react differently to similar circumstances. As Robinson states, the personal interpretation and judgment of an event is more important than the event itself (Robinson 1988: 32). In the following I present three different ways of narrating the experience of Multiple Sclerosis.

3.1.1. Normalization

3.1.1.1. Association

> I have MS, but MS does not have me. That's basically the way it is, my whole life. My illness is here, but it doesn't control my life. I am not thinking about it all the time. Yes, I have MS, but it does not have me. In many ways I feel that I am still the same person before MS. I know I am not able to walk so well, but I don’t say I am not able to walk because of MS. I don’t think this has been a change, because of MS. I just continue with my life as I used to.

This quote comes from Peter. Arranging a first meeting with him is difficult, as he at first does not feel well enough to meet me, and then cannot leave the house because severe weather conditions make him feel unsafe. When I visit him in a suburb of Dublin, he picks me up from the bus stop using a walking stick. We cross at a stoplight, and walk a few meters to a pub. During our conversation he tells me that these few meters already exhausted him. Peter is fifty years old and, as he tells me at the end of our second conversation, in a relationship with a man from Japan. He received his diagnosis in November of 2002. The months before his diagnosis were very hard for him since he did not know what was going on with him. Although he suspected that he might have Multiple Sclerosis since his mother has the same disease, his reaction to the diagnosis was shock. The uncertainty and fear of the future led to three months of depression. Physically he went down very quickly in the year of the diagnosis. Whereas in February he was almost healthy in November he was already very limited by his illness. Peter states that almost every part of his life had been affected by his illness. He had to quit his job, which had been very important for him and gave up driving. Moreover he has lost many of his friends; partly because he could not keep up with them anymore, and partly because some people were afraid that his illness would be contagious.

Yet, Peter emphasizes that he now is very close with the friends who are left and that he spends more time with his family. To him it is important that his two good friends treat him as a normal rather than as a disabled person. He underlines that it is necessary to talk about one’s condition. Therefore he visits meetings and seminars of the MS society. Another crucial aspect for him is to go out and leave the house regularly. He tries to take a little walk every day and if he is tired he stops at a pub where he drinks a coffee. To keep trying and not to say ‘I can’t’ is one of his mottos. In the interviews this is clearly demonstrated when he insists on getting us a cup of tea although it exhausts him. Probably he wants to show me that although something can be challenging, it does not mean that one cannot do it. According to him, he got his inspiration for this attitude by observing nature.

> I started seeing different things related to humans in my garden. I couldn't read at that time, so I just had to sit there and think...and this is where my belief started to come in. Even before I was diagnosed, can't remember if it was before August or in August, but I remember staring at a small plant. One branch was sort of broken and it was dying, but the rest of it was okay. Is this not like a person having something wrong with the hand or leg but the rest of the body is surviving and surviving okay? That's where I got my inspiration from; just looking around.

In the following he tells me that he considers himself to be rather lucky in terms of circumstances. Years ago before he was diagnosed he bought himself a bungalow, which means that everything is on the same floor and accessible. Furthermore, he made little adjustments in the house so if he had to use a wheelchair he would be prepared. Peter underscores the importance of not assuming the worst, since this may mean that the worst becomes reality more quickly. He also considers himself lucky because when he had to quit his job he received a sick pension; had he stayed longer and been fired he would not have received the same amount of money. Another positive aspect of his illness is that he gets to know his neighbors better because he can spend more time with them. Though this might sound as if he compulsively is trying to find the bright side, I have the impression that he genuinely appreciates having more time for the people around him. Peter accentuates that people often assume that it must be terrible to have an illness like Multiple Sclerosis or to be in a wheelchair. Yet he thinks this is not necessarily the case.

> It could be much worse, I could be in a car accident, be in a fire...this would limit my daily life more than MS. What would be if I would have to stay in bed 24 hours a day? What would I do then? I think everybody has something wrong with them. Maybe they didn't notice... MS to me, it is okay. Some people say, ‘oh you have MS, that's awful, how do you cope?’. And when you're in

> a wheelchair they say ‘oh that's terrible’. I say, ‘is it?’. For me it is not as awful or terrible as having to stay in bed and maybe not being able to do anything. I could be in a coma for many years. So erm, yeah, I do think myself lucky.

Though Peter describes a positive transformation his illness experience is not really characterized by personal growth as he does not express that his situation now is better. In his illness narrative, adaptation and returning to the normal stand in the foreground. He distances himself from people who are very focused on their illness, blame everything on it, and give up easily. In contrast he accepts his situation and attempts to do as much as possible. “When ill people try to organize their lives, they weigh and measure what they can do and the importance of doing it; they make trade-offs” (Charmaz 1991: 143). Thus, Peter focuses more on the activities he really wants to do and which have priority. He has learned to accept that not everything can be done in one day; postponement is acceptable. Moreover, he does not let his illness control his life. He feels that his illness affects only his body, but not necessarily his personality. One can argue that he separates his mind from his body. Peter expresses that he does not think much about his body. When I ask him about his body, he realizes that most of the changes that are happening are bodily changes. Yet he tries not to ascribe his limitation to his sick body, but to causes everybody experiences.

> If you can’t do anything, don’t blame it on the MS. You can blame it…maybe you’re just tired today, don’t say you’re tired because of the MS. Just say you’re tired.

Instead of dwelling on bodily changes, Peter tries to find a solution or alternative to a problem. He, for examples, has developed a different technique to hold a computer mouse or hold his walking stick so that he can still use these objects. One could say that Peter is normalizing his body, just as he normalizes his illness. That said, Peter is aware that his attitude may change in future: while he states that at the moment he accepts his body, he does not know what will happen when he has to be in a wheelchair. I find Peter’s story believable because he takes time and effort to answer my questions and reflect on his answers (both conversations take about three hours each). It does not seem that he wants to create a certain impression of himself. I rather think that he is curious about what his answers are because he has not thought about certain issues earlier.

Another informant whose narrative is characterized by normalization is Anna. She is thirty-five years old and single. She was diagnosed with Multiple Sclerosis in 2003 and still works full-time in a disability organization. Her symptoms include fatigue, urinary incontinence, balance problems, and a general weakness. Therefore she has to use a walking stick for short distances and a wheelchair for long distances. We meet two times in a pub near her work. The atmosphere during the interview is informal, which is amplified by the location of the interview. Anna states that it took her some years, but that she has accepts her illness now.

> For good, being honest, good three years...it was the first thing I thought and it was my major thought during the day and the last thing I though at night. It was not really worry, but it was on my mind all the time. But it's not anymore.

She underlines that in the beginning she talked a lot about her illness and read every book about it. Yet at a certain point she bored herself and her illness slowly became a normal part of her life. She expresses that now she is more comfortable with herself and with her identity. Her friends and family helped her through this process. It was crucial for her to be able to talk about her illness and have people who listened to her. Besides, she expresses that although she cannot do everything that her friends do, she does not feel inferior. Being able to work is another capacity which is important to her. As she works in a disability organization, she has been in regular contact with people with disabilities, and therefore being disabled became less terrifying for her. Furthermore she searched for a new hobby which would not involve physical exertion. Now she hosts a small radio show. Another major factor is that Anna judged herself through her studies she completed some years ago, her friends and family. As those aspects remained constant in her life, she states that she is better able to deal with her illness.

However, there are a few things that are still difficult for her. She is afraid of being labeled when she meets new people. She stresses that she is ‘quite more than her walking stick.’ To tell strangers about her diagnosis is challenging for her.

> I just say I have MS, I don’t, you know, I say I have MS, I am grant most of the time, but you know, there is stuff I can’t do. Stuff I will never, you know…I kind of go, well look, I am still me, but it is an issue. I rather want people to know than not know. So I wouldn’t be the type of person to try and keep it hidden, because I couldn’t imagine anything worse. Constantly having to sit down so that people do not see you walking. I couldn’t do that. But yeah, you know, you kind of like to think, well people will see me for who I am and what I am rather than to see the disability. But that’s easy for me to say. Not everyone is like that and in fact, most people aren’t. It can be a bit hard. But then you kind of go, that’s them. I am who I am, if they can’t accept me, well then…It’s who I am, if they can’t accept me, well that’s it. But that sounds all very nice and easy,

> but it really hurts like hell, but you know, that’s the truth. My MS is not going anywhere, I have it. So you either like me with it or…I can’t decide I have MS and I don’t have it tomorrow, you know I have it. So it a nonnegotiable thing. If people don’t like it, well then, sorry, you know there is nothing I can do about it, you know.

In this part of the interview she becomes a little melancholic, since she and her partner separated because he was not really able to deal with her illness. Anna tells me that he wanted to be able to deal with it, but in practice he could not. In the quote she struggles with the fact that there are things she will never be able to do anymore. She must confess that this is hard for her. This is reflected in her fast way of saying it and then quickly moving on to another aspect. On the whole, however, she emphasizes that she does not dwell too long on the things that she is not able to do anymore. Instead she underscores that she can still lead a relatively normal life. She is probably referring to the norms of society that expect an individual to work and to live independently. Her example shows that normalization does not simply mean that one’s illness becomes normal, but that it can also involve positive and negative experiences with the illness. Acceptance, for her, seems to include struggles with different periods in her illness. Her narrative describes a balance of positive and negative aspects; there are good and bad days (Charmaz 1991). Sometimes she is just fed up with her illness, but most of the time she is able to deal with it well. This, to me, makes her story believable.

Anna states that the relationship to her body did not change very much. Though she has to listen to it more, she says that she still perceives it in the same way. In spite of her fatigue, it is important for her to dress up and look after herself. My visual impression of her confirms this. She wears neat clothes and seems to have paid attention to her grooming. When she noticed that people often stare at her due to her way of walking, she changed her clothing style and now wears brighter colors. She states that if people are looking at her anyway, they can also look at her because of her clothes. With a smile she tells me that the issues she has with her body are not related to her illness; she just would love to be a bit taller and have bigger breasts. Anna has accepted the changes in her body, but her symptoms did not lead to a different perception of it. However, in our second conversation she admits that sometimes she gets angry at her body.

> I don't feel trapped in my body. There is sometimes, like not being able to walk down the pier and not being able to go for a nice walk on a Sunday afternoon, knowing that you gonna get half way down the pier, then you have to go rushing back trying to go to the toilet. And that is annoying there are times when I go, for Gods sake, I am sick of this, I am so sick of this and you do think, this is ridiculous...I kind of get really annoyed, but it passes.

In general Anna tries to find a balance between respecting the boundaries of her body and still being able to do as much as possible. I get the impression that she does not deny the problems of her illness, but does not dwell for too long on them either. Leaving the pub in her glaring red coat she attracts male attention. However it seems that as the men rather stare at her way of walking. I get the impression that, on the one hand she is used to those looks and maybe her red coat is a way of counteracting them. But on the other hand she still seems to feel slightly uncomfortable.

Another narrative of a person who emphasizes that she has accepted her illness and tries to live as normally as possible comes from Sarah. She is fifty-seven years old and was diagnosed when she was twenty-four. When I meet her, she has to rest in bed and cannot pick up her mobile phone because she does not have enough strength in her hands and arms. She is still able to live alone, but has eight caregivers and can only move around in an electronic wheelchair. However, she says that she has a positive outlook on life and that she adapted her life to the illness. “I suppose I am well-adjusted to it and I never get angry. I was talking to somebody yesterday about it. People often say, ‘why me?’ but I say, ‘why not me?’ That’s just another way to look at it”. It is debatable whether she never gets angry or whether she instead represses those memories. Sarah changed her lifestyle and channeled her interests in the things that she is still able to do. However, the things she names are listening to the radio and going out for ice cream. In comparison to what she did when she was less disabled, this is a huge difference. I get the impression that those changes were not as easy as they appear in her narration.

Sarah states that she gets a lot of visitors and still leaves the house regularly. Being disabled made her realize who her friends really are. This might imply that she also has lost many friends. It might be that she actually receives many visitors, but for me visiting her was similar to visiting a person who stays in a hospital. I believe that her social contacts have decreased as she cannot participate in many of her friends’ activities. Perhaps people now visit her more out of sympathy or habit. On the other hand, it might be that she has built up a strong social network although she is in a disadvantaged position. In addition she emphasized that people are really friendly to her, particularly when she is in the wheelchair. Again people could react out of sympathy, but Sarah does not perceive or acknowledge the situation in that matter. She states that she has accepted her illness and her situation and sees no point in fighting it. Although she emphasizes that she has always had this attitude, I wonder whether she did not have a period of struggle. The following quote shows that, in spite of her physical limitations she tries to lead a relatively normal life.

> I think people are inclined to think you don’t have a life, just because you are in a wheelchair. I used to find that, people [caretakers] would make, no they wouldn’t make an appointment, they would just call on me and then one day, three of them came here and I just was on my way out and I said, sorry I can’t wait, you have to ring me to make an appointment, and they were kind of surprised; they can’t expect me to be here. That’s good, because there are some people I know who don’t go out. But no, I still go out.

Thus, in spite of her severe disability and the restrictions that result from it she argues that she is still able to enjoy life. Sarah points out that her relationship to her body has not changed and that she accepts her body. She emphasizes that she does not feel alienated from it, but rather accepts it. The slow progression of the illness, which gave her time to adapt, coupled with the fact that she is already living with it for more than half of her life might be the reasons that she accepts her situation and her disabled body. On the other hand it could be that the situation is more painful to her than she confesses.

What stuck me when I first met Sarah was that although she is very limited by her illness she did not report many difficulties. It seems that she is transforming problems which are a result of her illness into problems that are caused by the inattention of her caretakers. She complains for example that they do not put her mobile phone or the receiver for the intercom onto her bed. As a consequence she cannot reach for them. Although this is a result of her illness she does not phrase it that way. Maybe this makes it easier for her to deal with her situation. Sarah acknowledges that she is very dependent on the caregivers, but also emphasizes that she is proud to still be able to live in her own house. This emphasis might be a reaction to an unconscious negative bias that I brought to the interview; perhaps I communicated a belief that somebody who has to rest in bed for the whole afternoon must have some difficulties. On the other hand it could be the case that Sarah, to a certain degree, wants me or herself to believe that she leads a happy life. After our conversation I felt sad and had the impression that it is not as easy for her as she tells me. Applying the concept of resonance, I felt that I recognized the need to pretend to the outside world, but also to oneself, that everything is fine. With other informants who were similarly disabled, but who also mentioned negative aspects and a struggle with the disease, I did not have this sentiment. Therefore I suspect that Sarah experiences or experienced difficult and painful periods which she left out in her story.

The first time I meet Patrick is in the MS Care Centre, where he is staying for a week in order to improve his condition. He is sitting in a push wheelchair and he has to be fed because he does not have enough strength in his arms. During our conversations I often hold a cup of coffee for him which he drinks with a straw. The next two times I visit him in the nursing home where he lives. At my last visit he reports that he is able to feed himself again and also appears to have more strength and energy. Patrick is forty-nine years old and very talkative. I hardly ask any questions and he tells me in detail about his situation. He was diagnosed with Multiple Sclerosis when he was twenty-four years old. He and his family reacted with shock to the diagnosis, but because his symptoms back then were not so severe he soon got used to the situation. He worked as a solicitor and accepted a job offer in Donegal, which lies in the north of Ireland and is sparsely populated. Partying on the weekends, he neglected his health, slept little, and lived mostly on fast-food. As a result his health worsened and he could not carry out his work as a solicitor anymore. Once he could no longer go out and ‘chase the girls’ he lost many social contact. He was disappointed in his friends because they did not change their activities so that Patrick could still participate. He instead tried to find friends in the MS society, but had the impression that except for the illness they do not have much in common with him.

> It is hard to meet new friends. I went to the MS support groups and self help groups, but I didn’t meet any people that I have so much in common. They seemed on a different level. It was hard to meet people I have things in common. It was a very difficult time. I kept going to all these MS parties and social groups, everything, but still, I wouldn’t meet people I could be friends with.

That time was difficult for him and he felt depressed. Reading self-help books and talking to new friends helped him to deal with the situation. Although he has come to terms with his illness and accepted the situation, he is not very happy with his body. He now is more conscious of it and feels that his posture changed as a result of being in the wheelchair for so many years. He reports that sometimes he feels trapped in his body. But he is not very motivated to actively change his body because according to him physiotherapy only depresses him by reminding him of what he cannot do. Therefore he only does passive physiotherapy, in which someone moves his limbs. It seems that by living for so long with a chronic condition, he has accepted it and does not see much sense in making efforts that will only reap small results. My impression of Patrick is that he sometimes tends to over-dramatize his story, but in general his narrative represents the way he experiences his illness. He seems to have accepted the need to ask others for help; I am kept busy holding his cup of coffee for him, reading out a text message he receives, holding the telephone for him, and getting him tablets. I surmise he also enjoys the female attention of me and of his caretakers. His level of disablement is similar to Sarah’s, but after conversations with him I do not feel sad. His story contains positive and negative aspects. I believe that he is busy with his daily life in the nursing home, his Polish girlfriend, his Russian caretaker, and other friends and people around him. Although his illness sometimes is difficult for him, I think his sense of humor and irony helps him to live well with his condition. His narrative does not completely fit into the category of normalization, as he also expresses some growth resulting from his illness. However, as growth is not central to our conversations, his narrative rather belongs to the category of normalization.

As the above narratives show, normalization encompasses two processes. On the one hand, people try to keep their old lifestyle and identity. They attempt to continue old activities and to diminish or disguise their symptoms. On the other hand, normalization can mean that people incorporate their illness into their life and change their lifestyle. They are open about their illness and do not hide it (Bury 2001: 272). In the words of Robinson, “‘[n]ormalization’ can be described as a strategy whereby, despite socially visible signs of the condition, a determined attempt is made to carry on life as normal, in which the disease is a part of that normal life, but not the dominant part” (1988: 51). People whose narratives belong to this category associate with their old reference group.

3.1.1.2. Disassociation

> I am more comfortable around them. Like sometimes I go to a [MS] meeting and I would not dress up when I feel rotten. Well, they wouldn't say to you 'God, you look awful' because they just accept you for what you are, because they know that they have been like that too. Whereas I think if I went out with my friends of the bank, you get a grilling 'God' and all that. Yeah, I think that's the main difference, really.

Caitlin is fifty-seven years old and lives with her husband in an apartment for people who are in a wheelchair. These apartments are autonomous; there are no caretakers, but they are specially built for people in a wheelchair. I visit her four times and meet her at a lecture about research on Multiple Sclerosis, after which she invites me to accompany her and her friends for a drink. Caitlin and her husband have one son who now lives in their old house. In 1998 she was officially diagnosed, but the first symptoms already appeared in her mid-twenties. After having a brain tumor she has to sit in a wheelchair, yet she hopes that she might be able to get out of it again. She has many difficulties with stress and fatigue. It took her a few years to come to terms with her illness and to be able to cope with it. In the beginning she denied her illness and did not believe that she really had Multiple Sclerosis. She just wanted to continue with her old life and did not want to have contact with other people in the same condition. But after some years she approached the MS society and is now very active as an advocate for the rights of people with a disability. She very much enjoys sharing experiences with people who have the same or a similar condition.

> That's why I like the MS meetings, because you see people like yourself and you can moan and complain. A good weight gets off my shoulders when I go there.

While she is comfortable with her peers, with her family Caitlin experiences her illness as problematic. Caitlin expresses that she gets a lot of extra attention because she is sick, especially when she had the brain tumor, but that she does not want to be in the center of attention.

> Family relations are badly. Anyone who has a chronic illness, the families suffer a lot. It is very difficult. Well you see, with families, like my son he doesn't want to upset me and he doesn't tell me things, because he doesn't want me to be worried. Maybe that happens in all families, I don't know. But I think it's because I have MS. And that's difficult. I think Adam [her husband] is the same, he thinks twice about telling me, about upsetting me. Because I get very upset, I would get into a frenzy, worrying about things, getting upset.

It upsets her that her husband takes over the education of her son. She thinks her husband has a closer relationship with him and that this is a result of her illness. As she mentions this repeatedly, it seems to worry her a lot.

Caitlin perceives her body as problematic as she is less mobile now. Asked whether her relationship to her body has changed she answers:

> Oh yeah, compared to what I did, I can't do anything, in the sense that my mobility is gone. I can't just jump out and say that I go to the shops. Well, I can, but it's a big job.

She sometimes gets angry about her body but most of the time she accepts it. Going to the gym every day she tries to make the best of her body and to regain the strength she lost after she had the brain tumor. Caitlin seems to be a person who likes to complain and to fret about many things. But I also get the impression that she herself does not take her complaints too seriously. During our conversation she gets emotional while talking about the death of her father, but not while talking about her illness. Thus at the moment she seems to struggle more with losses in her family and with her brain tumor than with Multiple Sclerosis. Her illness narrative lies in between normalization and loss. On the one hand she mentions many things she is not able to do anymore and that she has lost, but on the other hand she emphasizes that she is trying to do as much as possible and is getting on okay.

Caitlin's narrative describes disassociation, which means comparing one's behavior and attitudes not to the broader community, but to a local group of people with a similar condition (Robinson 1988: 51). Another way to describe this phenomenon is to say that people enter into a disability culture. A disability culture is characterized by a shared web of meaning, which means that people have a similar experience with impairments that limit their ability to function in the dominant culture. Furthermore, people are often active in a disability movement or meetings in which they share experiences (Harrison & Kahn 2003: 88). Disassociation is a means of normalization, but in relationship to a different reference group. In both types of normalization people "present the self so that illness remains controlled and delimited" (Charmaz 1991: 66).

About half of the narratives of people who participated in my research belong to the normalization category. In this category both genders, different severities of the illness, and different ages are represented. Positive aspects of the illness are not central to their perception, but people with those narratives express that they have a good quality of life and lead a more or less happy life. Except for Caitlin and Patrick, they do not perceive their body in a different way. Although some people are very limited because of the physical signs of the disease, they state that their relationship to their body remains unchanged.

3.1.2. Loss

> I just used to be able to do a lot of things, and now, okay, how, okay…when I didn't have MS, everything was accessible to me. I could do anything. Now that I have MS, I can't do anything I want to do.

Sean experiences many difficulties with his illness. The interviews, which take place in a café, are in the form of conversation in which he asks me a lot of questions and we discuss different aspects of the illness. In the end of the first conversation he expresses that he is very happy to talk to me, because I am the same age and have a similar background and he never before talked about his illness experience so openly. Sean is twenty-four years old and was diagnosed three years ago, but he probably had his first symptoms about five years ago. His illness manifests itself mainly in fatigue and balance problems. Sean does experience a lot of problems with his illness and finds it very hard to live with it. "I don't like having MS at all, it's probably the biggest…it is just the worst thing that could have happened". He could not continue with his work as it was physically too exhausting. At the moment he is looking for a job and he would like to go abroad but because of his illness it is more difficult for him than for his peers. He also would like to travel around the world but because he has to get an injection once a month which is only covered by his insurance in Ireland, this is impossible. Moreover, he is not able to participate in sports anymore, which formed a large part of his life. In this way his illness is very limiting.

> Because I used to play Rugby for like eleven or twelve years, and now I can't do anything anymore more like that. I can barely, I went running about a week ago. I just can't, I just can't. I don't know. It's just depressing, I suppose.

This incident reminded him of the fact that his illness is progressive. His worry over this is reflected in his voice. He tells me that he think he is depressed because he thinks almost every hour about his condition. The biggest and most frightening problem is that he does not know what will happen in the future, nor how quickly his illness will progress. Furthermore he has the impression that his illness stops him from doing a lot of things. Sean rhetorically describes the impact the disease has on his life by emphasizing that before he had Multiple Sclerosis he was able to do anything, and now he can do nothing. He tries to focus on the things that he still can do, but somehow he is caught up in the things he cannot do anymore.

> I would say my biggest problem is myself. I am my own worst enemy. That’s really like ahh, but I yeah, because I always say to myself, ohhh you can’t do it anyway, so why even try, which is really bad. I just I have to get into the right frame of mind. I have to start thinking, you can do what you can do. It is hard. Would it be the same with you, would it?

This quote demonstrates that he is insecure about the way he feels and thinks about his illness. He wonders whether his thoughts are typical for someone with such an illness or whether he is depressed. By asking me about my experience he tries to find out whether his way of thinking is ‘normal’. Sean feels very uncomfortable with his body. Asked whether his relationship with his body has changed he replies:

> Yeah, because I feel like I am trapped in a body that is not mine. That’s the easiest way to say. I don’t like the way I feel, sore, when I wake up I have pins and needles and stuff like that. Yeah, I don’t feel like I belong in my body.

Thus, his relationship with his body reflects how he is feeling about his illness. His age also plays an important role in his illness experience. Since he is at the beginning of his life, he cannot, like some older people I talked to who got Multiple Sclerosis at a late stage of their lives, look back and say that he has had a good life so far.

Connor’s narrative also contains many difficulties surrounding his illness. He is fifty-nine years old, has two sons, and is getting divorced from his wife, with whom he still lives. He was diagnosed about ten years ago and has to use a walking stick to move around in his house. Outside he can only walk small distances and therefore uses a push wheelchair. I meet Connor three times over a period of two months. When I first meet him at his house he just had a car accident and thus could not use his car. This depresses him, as he states that he normally would be a bit more animated. His mood is visible in his clothing style. When I meet him at eleven in the morning he is wearing a bathrobe and is barefoot. His voice sounds more depressed than when I meet him towards the end of my fieldwork period. The first part of the conversation is very formal, and it becomes obvious that he neither asks for nor accepts help. Since it is very cold in the living room, he goes through the difficult process of getting down on the floor to plug in the heating. As I see him struggling I offer my help, which he refuses. Then he gets a small table from the hall so that I can put my voice recorder on it, again without accepting my help. However, when he suggests we go into the kitchen and have a cup of coffee the atmosphere changes. He becomes more relaxed and talks more openly.

Although in our final conversation he was more animated than in the first two, he still experiences many difficulties with his illness and finds it very limiting and isolating.

> It is more or less taking over my identity, really, you know. It is taking over my identity. It limits what I can do. I used to do amateur, dramatics, amateur acting you can't do that at all. It is out of question. I don't travel abroad now at all. I don't, I have no ambition. I don't want to, it is too much trouble I don't want to go to places. I've tried it but it is too difficult getting around…I don't. I am much less inclined to travel. I wouldn't really go anywhere. I wouldn't even go, I wouldn't even just go to town. So, it's limiting that way, certainly.

Apart from not being able to travel, his social activities have decreased; since he has to be in a push wheelchair, in which he depends on the help of people, he does not enjoy meeting with them. He states that people do not like a bad-tempered disabled person, and he therefore feels he must always appear happy and grateful. He is afraid that if he refuses help people will not offer it anymore. As a result he feels unhappy. Being in a wheelchair for him is a negative experience. According to him, people think he is pathetic. To avoid the pitying eye contact of others, he wears dark sunglasses while he is in a wheelchair. Cultural context thus shapes the way he perceives his illness. But as other informants did not report similar negative experiences, the reactions of others are obviously shaped by the way people feel and behave while in the wheelchair. However, Connor still obviously retains a humorous side: he tells me that he sometimes amuses himself by saying aloud "oh yeah, that was before my helicopter crash…oh yeah, I remember that well, that was before my helicopter crash". Yet, he feels alienated from his body and much older than his actual age.

> I feel much more, how do you call it, I feel antiquated, you know, I feel old or something, because you are holding on to stuff and all that kind of stuff. It is as if all of a sudden you'd be ninety years of age, you know, dumpling around, looking here, looking there. Careful where you step, you know. The whole process has slowed down so much, so you would feel that, yeah.

In these two quotes his voice does sound rather depressed. This slightly changes in our final conversation. Moreover, he is normally dressed although one sock is only half put on. He begins telling me that he has been away for a weekend with the MS society and that he enjoyed it. Moreover, he has decided to get an electronic wheelchair. Initially he did not want to be seen in an electronic wheelchair, but now he feels that he will be more independent with it. In general there is a striking difference in that he focuses more on the positives and on the things that he is still able to do.

> Yeah, one of the huge differences, the difference between being able to stand and move even if you've to hold on to things, it's huge, you know what I mean. The difference between being a little bit mobile but being able to walk over to my desk and to the closet and take my own coat, put it on, get into the chair and go. If I wasn't gonna do that, that made a huge difference. I'd had to wait for someone to lift me up, I had to wait to go, if I need a coat the coat had to be put on me. I had to wait until they put it on me, that piece, that minor piece of difference, being able to get up like that [stands up] and not being, is huge!

It is remarkable how his voice changes in our third conversation. While in the first interview he associated 'holding on to stuff' with being old, he now emphasizes that he is still able to walk even if he has to hold on to things. Furthermore, he is more humorous and sees a comic side in being disabled. He points out that having black humor can help dealing with such a situation. But although his illness narrative is slightly more positive than in the first two conversations it is still characterized by the experience of loss. He does not consider that he is living a relatively normal life, but he also tells me that Multiple Sclerosis is not the worst thing that has happened to him. In our second conversation he tells me that he and his wife lost a child, which was very hard for him, and in our final conversation he confides in me that he is an alcoholic. Thus, his way of experiencing his illness is related to his other problems.

Connor also experiences his body differently. He feels disabled and much older. In his opinion his disability is more important than his clothing in shaping other people's perceptions of him. When he meets me in his bathrobe in our first conversation, this highlights to me that he is struggling and lacks the motivation to get dressed for the day. However, one has to take into consideration that getting dressed for someone with Multiple Sclerosis can take a lot of energy. In contrast, at our third conversation he is normally dressed and more positive.

Another person with comparable difficulties in confronting his condition is Richard. He is thirty-eight years of age, married, and the father of a young boy. For ten years he has been living in Australia, but because of personal circumstances he returned to Dublin, where he has now lived for almost three years. His MS was diagnosed shortly before he returned to Ireland. He suffers from a general weakness in his body, tiredness, pain, has bladder problems, and special difficulties with his right side. He cannot write anymore or hold objects in his right hand. The following quote demonstrates how Richard experiences his illness. When I ask him what his reaction to his diagnosis was, he answered the following:

> Shock, disgust and anger, you know, complete shock, annoyance. Why me? What can I do about it? I thought I was gonna die, I thought it was the end of the world, especially with a new child and then being so far away from home. So, but you know I think I am a fairly positive person and I… three and half years later it's not fine, it's still acting about it every day, coming into my head every day, coming into my head several times a day. I don't …I like to say I don't really get fatigue which a lot of people do get, but then again I do get, like today I was quite tired, this morning I was quite tired…I think because I had a bad night sleep, and I try not to let it get me down, so I focus on the positive. One expression that I heard last year is, 'pain is a given, suffering is an option'. So you can decide to sit back and take it all and do nothing at all or you can decide to get on with life and I think that's really what I am trying to do, focus on the positive. Yes, the pain is there and it is an issue every day. And there is always an issue, that come and go. I probably work, probably stressful enough job that's relatively high power in terms of what I am doing. So I work quite hard, I probably work too hard in my work. Anyway I have to pay the bills. Ireland is not a cheap place to live and you have to pay for everything and it's …so I work quite hard, I work between seven and ten hours a day probably. And I manage it, you know I am. I can work from here and do things on the road and things like that…so it's not too bad, so I can get through get on by…I get on by. Shock, anger, disgust, annoyance, why me. That's it. That was my reaction. Next question.

His answer contains different information. It seems like he has been asked this question before, as he answers rather quickly. Maybe he has a counselor with whom he has already talked about these issues. This would show that he needs support in dealing with his illness. The discrepancy between his statement that, on the one hand he is a positive person and on the other hand that his illness is still on his mind gives me the impression that he wants to maintain a positive attitude, but is unsuccessful. He is aware of this discrepancy; it seems that he is questioning his self-perception and admits that his illness worries him a lot. By repeating the emotions he associated with his diagnosis, he emphasizes that these are still central. Although he tries to carry on with life his illness still strains him a lot. By asking what my next question is, he reveals that talking about this arouses negative feelings he would rather not dwell on.

Although his work is very stressful for him, he is grateful for it. His income is secured and work distracts him from his illness. His work might be an escape from his illness and a way to prove that he is still worthy. The following quote demonstrates the losses he experiences as result of his illness.

> It is not being able to do things as confidently as I did in the past. Not being able to run, not being able to be active as much as possible, not being able to play with my son. Not being able, I can't play football, not that he plays football, that much either but…Not being able to do things like that, the activities, not being able to jump on a trampoline, not being able to…not that he does much jumping on a trampoline…But not being able run away and hide and do things like that. Not being able to carry him, my wife can carry him. My right hand, my right arm is quite weak so I wouldn't be holding him or anybody else. My left arm gets more used now and so it gets more…fatigue, that's been used much more. I never hold a hot cup, I never hold anything, my right hand would cause injury to me or anybody else. So it's a juggling act really and that's the main change. So yes, sports, simply most of the things, read, I can still watch TV, still watch, still drink pints, you know, drink beers. Probably not supposed to drink that much, because of medication but life's too short …so yeah, it's okay, you know.

This quote reflects his struggle with his disease. On the one hand he experiences many losses, from large ones like not being able to play with his son, to small ones like not being able to hold a cup. But Charmaz remarks that the "[i]nability to handle routine tasks evokes existential dilemmas about self-worth, living at all, and limitation. Dropping the trash takes on magnified meaning" (Charmaz 1991: 137). With Richard this is certainly the case. On the other hand he tries to focus on the things he is still able to do, like watching television and having a beer. Yet, those aspects do not really seem to compensate for his losses. Moreover his last expression that it is 'okay' seems an attempt to convince me or himself, but does not seem to reflect how he really feels. His aim is to be as normal as possible and when people ask him what is wrong with him he would say that he has a sore arm or back. Although he wants to be a normal person, he is unsuccessful. He thinks about his illness every day and is very negative about it. This may be connected to how recent his diagnosis is. In general Richard states that he does not perceive his body differently. However, he mentions that he sometimes sees his right leg as useless. Quickly he adds that this does not make him useless and that he is trying to think positive. But again it seems as if he is narrating his situation more positively than he actually is experiencing it.

When I meet Richard at his home, I wonder if he has relatively mild symptoms, since one must climb two staircases to get there. When I soon find out that the stairs are indeed a problem for Richard, I see it as a reflection of Richard's desire to come across as strong and deny his difficulties. When he carries my backpack for me, my impression is strengthened that it is important for Richard to maintain a positive image of himself to other people. He tries to emphasize that he is all right and dealing well, but to me this does not reflect his illness experience. It seems that theoretically he has figured out how he should think and act but in practice this is still difficult for him. Leaving his house I feel sad. I believe that certain aspects of his story resonate with my experience. I also pretended to others and to myself to be in control of the situation and know what an effort this can cost. I did not want to depend on others and initially was too stubborn to ask people for help. Under the impression that I could not talk to anyone, I felt isolated. I know how painful these aspects can be, and I suspect that although Richard did not express this pain to me, he felt it. I believe that his diagnosis still is very recent for him and he needs time to adapt to the situation.

About one quarter of the illness narratives of my informants can be ascribed to this category. People with these narratives ranged from age twenty-four to fifty-nine and were mostly men. Different kinds of disabilities are represented in this category of illness narratives. However, for the most part informants with those narratives had rather mild forms and were less disabled than people whose narratives belong to the other categories. As these empirical examples show, the biggest problem for them is that they cannot keep up with their old lifestyle and do not want to give it up. Moreover they cannot pursue their dreams anymore.

The difficulties that are reflected in these narratives are consistent with the problems identified in the literature about chronic illness. According to Charmaz people with a chronic illness are confronted with different challenges. For some a chronic and disabling illness can affect their lives to a large extend. “A fundamental form of that suffering is the loss of self in chronically ill persons who observe their former self-images crumbling away without the simultaneous development of equally valued new ones” (Charmaz 1983: 168). Their varying awareness of their restrictions is colored by values of independence and individualism, which intensify the impact of chronic illness. People suffering from a chronic condition can experience a loss of control, which according to Charmaz results in a loss of self. Furthermore, the unpredictability of the illness fosters fear and uncertainty (*ibid*.: 171-174).

Social isolation is another problem which confronts people suffering from a chronic and progressive illness, especially when they cannot pursue work, sports, or other leisure activities. When they must rely on visitors, who must take extra time and effort to visit them, they are sometimes shocked by the negligence of their former friends and relatives. Another consequence is that people believe they are becoming a burden to others, which also negatively affects their self image and self esteem (*ibid*.: 176-188). People also might have the impression that their disability is overshadowing their identity (Susman 1994: 19).

Deconstructing Sean’s illness narrative many of those aspects appear. As he can neither do sport nor go out with his friends, he feels limited and isolated. He experiences a loss of self as he loses the activities he based his identity on. The worst aspect of his illness is its progressive character and the uncertainty that results from it. In the narrative of Connor these aspects are also reflected. He feels restricted in his life as he cannot do the things he likes anymore. He has the impression that his disability overshadows him and that people only perceive him as a person in a wheelchair. Although he does not want to burden people his illness forces him to depend more on others. Likewise, Richard feels that his illness limits him as he among other things cannot play with his son anymore. It concerns him that he does not know how fast his illness will progress and whether in the future he will be able to provide for his family.

3.1.3. Posttraumatic 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[3], not knowing what was wrong with him. This period was very difficult for him and he

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[3] Ireland only has about twelve neurologists for a population of 4.400.000 people.

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 though 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 readdress, 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.[4] 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, where I met him twice for the interview. This work gives him a lot of satisfaction. He states: “My life is good and I am enjoying 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

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[4] The basic principle is that via tapping on the meridians of the body psychological and physical problems can be solved.

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 the second conversation 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. It is therefore important as I noted in the introduction to take the context of an interview into consideration, because it can strongly color the informants answers. 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.

Although he mostly focuses on his positive transformation, he perceives his body differently and finds it difficult to deal with the bodily changes.

> Do I see my body differently? Yes I do. I am not the man I was. I can’t do the things I liked to be able to do, anymore. I can’t no, and that’s a very hard thing to accept. I suppose that’s the hardest thing at the moment looking at me now and looking at me then, what I am able to do now and what I was able to do then, it is hard to accept. It is hard to give in to the fact that I can’t do it [his mood changes].

Alex realizes that his body is much weaker now. However, he states that he does not have a problem with his body and is not alienated from it. The case of Alex is very interesting because 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 whose narrative belongs to this category is Samuel, who in some aspects has a similar background to Alex. 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 tells me that he has 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 sister 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 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. The same goes for his body. At the moment he does not perceive it differently and does not feel alienated. 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, whom I introduced in the prologue, belongs to the same category. I meet Emily three times in the MS Care Center where she works at the reception desk. She is fifty-two years old and she 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. She has a good social network; 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 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. This is reflected in the ways she experiences her body. She states that she loves her body and looks after it better. Although she tends to go for the limit she underlines that she is in touch with her body. 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 the negative sides. In comparison to the struggles she fought before in her life Multiple Sclerosis seems to be only a minor issue.

About one quarter of the narratives belong to this category. The people in this group are all above forty years of age. Both sexes and different grades of disability are represented. Persons in this group have been diagnosed for different periods of time. One person’s diagnosis dates back to 1988; another person received his diagnosis only in 2007. Some people already use a wheelchair; others are still able to walk with the aid of a stick. 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, a concept derived from psychology. 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 let to a negative bias in analyzing the outcomes of traumatic events. Scholars saw the experience of posttraumatic growth as a coping strategy or as an illusion. 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 (*ibid*.: 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 new paths (*ibid*.: 6). 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).

All informants whose narratives belong to this category state that before their diagnosis they pretended to the outside world that they led a good life, but were feeling unhappy inside. However, they argue that some time after their diagnosis they actually felt happy inside. Those people used their illness as a springboard for personal development (Tedeschi *et al*. 1998: 1). Alex, Samuel and Emily now have a greater appreciation for life and their relationships have become more meaningful to them. Although some scholars state that the experience of posttraumatic growth is merely a coping mechanism or an illusion, I am of the opinion that for those people the experience is real and that they actually changed their priorities and outlook.

3.2. Discussion

In this chapter I discussed three ways of narrating the experience of Multiple Sclerosis, related by informants with various grades of disability, different ages, and different backgrounds. The majority of narratives fall into the category of normalization, either continuing with their old lifestyle or adapting it to their illness. Most narratives describe normalization with regards to a person’s old reference group, yet some narratives display disassociation, or normalization with regards to a new reference group, which mostly consists of people with a disability. One quarter of the narratives are of people who experience many difficulties integrating their illness into their lives and mostly focus on the discrepancy between the things they would like to do and the things they actually can do. The experience of loss is in the foreground. However, the other fourth of narratives display an experience of posttraumatic growth. People with those narratives transformed their lives in a positive way as a result of their illness. They express a greater appreciation for life and have more meaningful relationships.

Interestingly, theories about illness narratives describe and acknowledge variety. Yet, theories about illness experience often assume that there is a common experience of disruption or loss that all people share. As I found a variety in people’s experiences, theories about illness experience should be reexamined. It is important not to assume that everybody who has a chronic and disabling illness has the same experience. Illness narratives are a powerful way to give voice to the patient’s suffering (Hydén 1997: 49; Riessman 2003: 6). For Kleinman it was important to give voice to the suffering experienced by people with a chronic illness (1988), yet in my research a majority of my informants would not say that they suffer from Multiple Sclerosis. They preferred to simply say that they have MS.

The body plays an important role in the illness experience. The majority of people expresses that they have to pay more attention to their body. They listen more to it than before they were diagnosed and are more aware of its boundaries. People have to find a balance between respecting the boundaries of their body and doing what they want to do. They have to decide what is more important to them: meeting their friends and feeling exhausted afterwards, or feeling well but staying at home. Some prefer to do as much as possible and hazard the consequences of exhaustion: others restructure their lives and find compromises which enable them to be socially active without pushing the boundary of the body too much.

As Douglas (1970) pointed out the perception of the natural or individual body is shaped by the social body. Initially many people have difficulties using a walking aid and being seen as a ‘disabled’ person. Their trouble probably results from their perception of the social context. It also seems that how they perceive their situation is reflected in how people treat them. Before he was diagnosed, Connor avoided looking at people in a wheelchair; now, he feels that people look down on him. The single time Peter used a wheelchair in a shopping center, he found that people would talk to the person pushing the wheelchair and not to him. In contrast Emily, Sarah, and Caitlin, who underline that they are communicative and have accepted their situation, express that people are friendly to them when they are in the wheelchair. They do not have the impression that their disability overshadows them. This might indicate that for men it is more difficult to be in a wheelchair, because society expects them to be strong and independent. Women might in general be seen as fragile and dependent and might therefore experience fewer problems with being in a wheelchair. Furthermore, with regards to Multiple Sclerosis, sickness and disability often are only visible when people move. It is hence important to realize that the body is a moving entity. Another factor shaping the way people experience their body and illness is what Scheper-Hughes and Lock (1987) term the body politic. Since in Ireland the medical sector is not consistently developed and people might have to wait for a long time until they get diagnosed and receive medical treatment, people might experience more difficulties with their situation.

Finally, as the empirical examples demonstrate the experience of the body is related to the illness experience. People who strive for normalization do not perceive their bodies differently. They have accepted their limitations and found a way to deal with them. On the other hand people whose illness narrative is characterized by loss perceive their body as problematic. They feel alienated and experience disunity between body and self. Yet, people who experience posttraumatic growth mostly accept their body and some state they love their body. Hence, the illness experience and the experience of the body are connected. As people all have different grades of disability they are dealing differently with bodily restrictions. While one is getting used to being in a wheelchair and accepts the situation, another might perceive the same situation completely differently.

4. A Multi-factorial Analysis of the Illness Experience

In the previous chapter I discussed different illness narratives about the experience with Multiple Sclerosis. The question that arises is: how can these differences in illness narratives, and thus also illness experiences, be explained? Why do some people experience many problems with their illness while others are able to deal with it well? This question is addressed in theories about resilience. “Resilience refers to a dynamic process encompassing positive adaptation within the context of significant adversity” (Luthar *et al*. 2000: 543). In other words resilience refers to the capacity to bounce back after a traumatic event. The emergence of resilience theories is the result of a paradigm shift. Whereas earlier research mainly focused on risk factors that led to psychological problems, now more attention is paid to protective factors and positive adaptation (Richardson 2002: 309). Originally, resilience was studied in children at risk, but later was applied to other groups. Resilience can also be analyzed in the experience of chronic illness. Kralik *et al*. criticize that there is a negative bias within the health discipline, which focuses on deficits and problems rather than on strengths and capabilities (2006: 198).

The aim of resilience theory is to identify factors that can explain why some people bounce back after a traumatic event and others not. Studies about children at risk bring forward the argument that parental support is related to the resiliency of the child (Spaccarelli 1995: 1179). With regards to chronic illness the following factors are believed to determine how well people deal with their condition. First, the awareness of the condition (to what extent people believe they are actually sick) plays a role. Second, ways of coping and managing the illness are considered to be important. Third, relationships with others and perceived social support shapes the way people deal with their illness. Forth, spirituality and hope are mentioned. Fifth, courage and how people handle difficult situations which result from their illness is crucial. And finally, reported quality of life, which is related to confidence and self-esteem, is identified as a factor (Haase *et al*. 1999: 127).

In the course of my research different factors were explored that could explain for the variety of illness experiences, which I now explore in this chapter. These factors partly derive from resilience theory, like social support and spirituality; others are more specifically related to chronic illness, like the severity of the symptoms, visibility, time of the diagnosis and dependence. I added the factors of lifestyle changes, work and gender, because I believe they could shape the way people experience their illness as well. First, I discuss the impact of lifestyle changes on the illness experience. I divide this category in different sectors, namely changes in the social network and the social support of family and friends, changes in employment and changes in leisure activities. Second, I focus on individual factors such as time of the diagnosis, gender, age, and symptoms or functional disability. Third, I analyze to what extent spirituality shapes the way people experience their illness.

4.1. Changes in Lifestyle

4.1.1. Social Support

The social support people receive can play an important role in the way people experience their illness. “Social support is defined as the degree to which the individual’s need for socialization, tangible assistance, cognitive guidance, and emotional sustenance are met through interaction with the social network (Hirsch 1980)” (Wineman 1990: 294). In other words social support is experienced when a person feels “believed in” (King *et al*. 2003: 197). Being diagnosed with Multiple Sclerosis can present a situation in which an individual increasingly needs social support. Durkheim (1951) argued that the belonging to a group affects a person’s well-being. In contrast the absence of social integration can result in despair and hopelessness (Wineman 1990: 295). The support can consist of being able to talk about one’s problems or having somebody who accepts one as one is. Different studies (Maybury & Brewin 1984; Miles 1979; McIvor, Riklan & Reznikoff 1984; Miles 1979, McNett 1987) also suggest that social support can significantly shape the way people are able to cope with their impairment (Wineman 1990: 294). King *et al*. state that “[s]ocial support was by far the most common and important helpful factor” in living with a chronic disability (2003: 197).

For Anna (35) whose narrative belongs to the category of normalization, social support plays an important role as the topic appears several times in her illness narrative. When she was diagnosed in 2003 her family and friends were very supportive.

> My dad has been great, really, really supportive. He has just been fantastic. It hasn’t been easy for him, but he is really good; quite positive when I need somebody to be positive. My friends have all been fantastic, like really supportive. To be honest when I was diagnosed I just talked about it constantly. I think I bored them. They are really supportive. When I need someone, they will push me. They are very aware whether there are steps or anything. They have been great and now it is not the only thing I talk about. And I must say that without my family and friends I couldn’t have done that.

Her frequent use of the words ‘really’, ‘supportive’ and ‘fantastic’ demonstrate that she wants to underline how important her social network is to her. In general Anna deals quite positively with her illness and although she experiences difficulties she is able to lead a relatively normal life.

A similar picture emerges looking at the life of Sarah (57). Her illness narrative displays normalization. She is severely disabled and has to use an electronic wheelchair. In the afternoons she has to rest in her bed, where she can hardly move. Yet, she expresses that she leads a happy life and has adapted well to her situation. Hereby, her friends and family play an important role.

> I think people just accept me, accept that I am who I am and it’s good and it’s fine and they accept it. And my friends that I have for years and years all say to me that they see me as I was. They don’t really see me as disabled. That’s good.

The acceptance of her friends and family helps her to be able to positively deal with her illness. Although it can be questioned whether her friends really do not see her as disabled as she is physically very limited, what is important is Sarah’s perception. Indeed it seems that in spite of her physical restrictions she still receives visitors and participates in social activities.

Caitlin (57) illness narrative describes a disassociation. She has lost many friends because of her MS as she was ashamed of her condition. In addition she experiences problems within her family but receives a lot of support from other people who have Multiple Sclerosis or another disability.

> That’s why I like the MS meetings, because you see people like yourself and you can moan and complain. A good weight gets off my shoulders when I go there.

Thus, in all the cases talking about their illness and difficulties helps them to deal with their illness. In the case of Anna and Sarah, the social network mostly consists of family and friends who do not have Multiple Sclerosis, but for Caitlin peer support plays a crucial role.

The situation of Richard (38), whose illness narrative belongs to the category of loss, is different. In comparison to the participants named above he has very mild symptoms, but he does not receive much social support. Although he can talk about his problems with his wife, in his eyes she cannot provide much help. In general he does not talk much about his illness and wants it to be invisible. Furthermore he has almost no contact with other people who have Multiple Sclerosis, because in his opinion they would only get him down. He assumes that they do not have a positive attitude towards life and therefore prefers to surround himself with people who have a positive point of view and who can lift him up. “I just fight my own battle and try to integrate with normal society rather than hang around with people who have MS”. In general Richard suffers a lot from his situation and it seems that the fact that he is ‘fighting his own battle’ contributes to the difficulties he experiences.

These examples suggest that the social support a person receives can determine how people experience their illness. The more support a person gets the better the person seems to be able to deal with the illness. People who are accepted for who they are seem to experience fewer problems. Strikingly, all the people experiencing posttraumatic growth are in a relationship at the moment. But there are also people whose narratives describe loss or normalization and who have a partner. Thus, it seems people who have a partner tend to experience fewer problems, but having a partner does not necessarily lead to a more positive illness experience. The same applies for peer group support. For some people this support is very important, but the people experiencing posttraumatic growth are not in close contact with other people who have Multiple Sclerosis. Likewise, people whose illness narratives center on loss do not have close contact with other people suffering from Multiple Sclerosis. In general people striving for normalization had the most contact with other people who have Multiple Sclerosis.

During my research I also came across counterexamples. Some people have lost friends or do not perceive a lot of support from their social network, but are still dealing very well with their condition. Peter (50), whose narrative belongs to the category of normalization, is one example of a person who lost many friends because of his illness and does not receive much support. Yet he decided not to give up and to maintain a positive attitude towards life. More important than social support for him is that he keeps trying and accepts his situation. Thus, although his social network has decreased he is able to compensate for this by focusing on his individual strength. The case of Alex (55) whose narrative describes posttraumatic growth is similar. He states that many of his friends have difficulties with his conditions. According to him it is important that his friends still treat him like a normal person and not as somebody who is overshadowed by his illness. Yet in practice for his friends this is problematic and they often do not know how to judge his situation. Alex thinks they sometimes doubt whether he is sick at all. His wife also has difficulties treating him as a normal person. She often wants to take over tasks that in her eyes are too exhausting for her husband. But for Alex it is important to still be able to do things and at least to try. This problem is common among partners of people with Multiple Sclerosis. As the healthy partner can do tasks faster, he or she tends to take over the tasks (Robinson 1988: 67). Although he does not receive much support from his close social network he is able to deal well with his illness because he sees it as a personal journey which changed him for the better. In this journey he was stimulated by people with the same aim and who also wanted to make more of their lives. Yet those people do not belong to his close social network. His individual development stands in the foreground and overshadows the problems and lack of understanding of others. As these two cases demonstrate social support does not play a crucial role for everyone.

In summary, in accordance with the literature, social support can play an important role in how people experience their illness and how well they are able to deal with their illness. But my data shows that in contrast to the literature, the social support a person receives is not necessarily a determining factor in the illness experience.

4.1.2. Employment

Multiple Sclerosis can have a huge impact on employment. As a result of physical or mental restriction people might not be able to work anymore. “Approximately 70% to 80% of persons with MS are unemployed 5 years after the diagnosis is made” (Johnson *et al*. 2004: 201). A person’s identity is connected to his or her ability to work; earning income and being responsible for one’s economic condition can have a positive impact on one’s identity (Grytten & Måseide 2005: 236). Different studies emphasize the negative consequences, like loss of status and social roles, which can result from unemployment (Cunnigham 1977; I. Robinson, Lawson, and Wynne 1983, in Robinson 1988: 76). Interestingly, La Rocca *et al.* argue that the relation between physical limitations and unemployment is very complex. “The patients’ premorbid personalities and coping styles, as well as their ability to maintain an image of themselves as productive, working individuals may play a significant role in vocational adaptation (La Rocca *et al*. 1985: 210)” (Robinson 1988:

74).

Hence, the ability to work and to earn money can play an important role in how people experience their illness. For Emily (52) whose narrative describes posttraumatic growth, being able to work at the MS care center as a reception positively shapes the way she experiences her illness. “When I come to work, I am well. Maybe I feel I am worth something. Because when I am at home and not doing anything…it is just nice to go to work and be determined”. Emily’s description shows that she uses her work as a coping mechanism, since it makes her feel independent and capable of contributing something to society. Moreover she likes her work because she can help patients through her own experience. Employment, similarly, is important to Anna (35) who works in a disability organization. “Even after years of being diagnosed I still could do my job, I still could do my job and you know that was really important for me”. More people who are still able to work emphasize that this helped them deal with their illness. People, who had lost their work recently, like Sean (24) whose narrative is characterized by loss or Samuel (45) who experiences posttraumatic growth, expressed difficulties with this new situation and felt that they were facing more uncertainties. Interestingly, many people, who did not experience difficulties with their work, were employed in a disability or charity organization. People expressing more problems worked mostly in the financial sector.

From these examples it follows that the ability to work can positively shape the illness experience. Yet, concluding that people who do not work have a more negative experience of their illness is not valid. I also met people who had stopped working and after a period of adapting were coping well with the situation. Sarah (57), Patrick (49) whose narrative lies between normalization and posttraumatic growth, and Peter (50) have accepted that they cannot work anymore and do not seem to experience a violation of their self-confidence or identity. It might be possible that people found this very difficult but did not express this to me. Yet, from my general evaluation of my informants this did not seem to be the case. As a conclusion, the people whose illness narrative is characterized by loss were not all unemployed, nor were the people experiencing posttraumatic growth or normalization all employed. In general work can shape the illness experience in a positive way, but people unable to work do not necessarily experience, as described in the literature, a self-perceived loss of status and social role. Of course, this does not mean that society shares their positive perception.

4.1.3. Leisure

Some people are very restricted by their illness and have to change their lifestyle completely. For example, people with Multiple Sclerosis often cannot practice sports anymore. Sean (24) worked out a lot but had to drop out of most sport clubs. Not being able to participate in sports is a drastic change, which depresses him. In addition he cannot go out with his friends as he did before. “I try to keep up with my friends as much as I can, but I can’t”. He experiences many difficulties with his illness, because he cannot do what his peers do. Connor (59) whose illness narratives centers on loss had the same experience. He used to do amateur acting and went out a lot, but stopped because of his illness. As a consequence he feels very isolated and depressed. According to him his lifestyle now is very different from the one he had before he was diagnosed with Multiple Sclerosis. He is still able to work and lives with his family, but the fact that he cannot continue with his old lifestyle gets him down.

For those two men, their illness has decisive consequences for their spare time activities. It seems that the more drastic changes the illness brings in one's lifestyle the more problems people experience. In support of this view, Anna (35) mentions that her illness would be more difficult for her if she had been very sportive or outgoing. As she prefers to read a book or watch a movie with her friends at home, she does not experience so many changes.

> I was never really sporty, so I can’t run or I can’t do much in sport. For some people I could imagine it would be a big loss, for those who were very sporty. I couldn’t do it anymore. I was never great in sport. I am more, I like to read and go out with friend. I am more laid back.

The minimal changes in her lifestyle might be a reason why her illness narrative is rather positive and why she is able to deal well with her condition.

On the other hand I came across people who experienced drastic changes in their lifestyle, but who adapted well to these changes. Alex (55), for instance, was very active in sports and often went out with his friends and colleagues. Due to his illness he is restricted in that area of his life, but as he has found an alternative he does not mind. He now enjoys a glass of wine with his wife and is busy following a path of personal growth and development. He thus managed to turn the radical changes into a positive experience. Similarly, Peter’s (50) life changed drastically as he is not able to carry out a lot of things which he could do before he was diagnosed. He has decided to make the best of his situation and is therefore able to deal well with his situation. Sarah (57) also experienced drastic lifestyle changes as she was very athletic and played golf on a national level.

But she changed her interests and finds joy in the things that she is still able to do, for example listen to the radio or go out for a walk in her electronic wheelchair. Although in comparison these activities might seem minor, it is important that to Sarah they are meaningful.

As a conclusion, it is easier for people if the illness does not restrict their spare time activities. However, people who are able to find meaningful, alternative hobbies are able to live with the restrictions of their illness. Those who have the impression that their illness takes away all their enjoyable activities have more difficulties with their condition. If people have to give up their old hobbies it is therefore important that they find a new expedient activity.

In summary, the degree of changes in lifestyle (encompassing shifts in the social network, employment, and people's leisure time) does not predict how people experience their illness. Narratives of people who experienced drastic changes belong both to the category of personal growth and the category of loss. But one can say that the narratives of people who did not experience far-reaching changes mostly belong to the category of normalization. Thus, some people have many difficulties dealing with lifestyle changes while others are able to transform them. Those people find meaningful substitutes for the activities they are not able to do anymore. Moreover the people whose narratives describe few problems are accepted by their friends or have found a new group of friends.

4.2. Individual Factors

4.2.1. Time of Diagnosis and Age

In general all informants needed some time to come to terms with their illness. Some went through a period of denial in which they did not want to believe that they had Multiple Sclerosis. After a few months or years, however, they accepted their situation. But often people expressed that they only accepted their current situation. They are uncertain about how they will handle a further progression of the illness. One could suppose that the longer people have been diagnosed the better they can deal with their situation, as they have more time to adapt to it. Matson and Brooks argue that going through a transition from denial to acceptance and integration of the illness leads to better adjustment (Robinson 1988: 33). However, other scholars criticize that, on the one hand, this statement is not yet substantiated by empirical research, and on the other hand, that the relationship between the length of illness and the way of dealing with it is not that simple (*ibid*.).

During my fieldwork I noticed that people who have been diagnosed for more than ten or twenty years have adapted relatively well to their situation and experience in general fewer problems, while people who have been diagnosed for a relatively short period of time described more loss. Sean (24) and Richard (38) have only been diagnosed a few years ago and their illness narrative belongs to the category of loss. But on the other hand, Samuel, who was diagnosed after Sean and Richard, is able to deal well with his illness. Alex (55) also was diagnosed a relatively short time ago but is managing well.

In addition the age of a person can play a role in the way they experience Multiple Sclerosis. In general people who are diagnosed later in life have a milder form of the illness. But it does not make a large difference whether people are diagnosed early or later in life. People at every stage of their lives might have the impression that their illness limits them in pursuing their dreams. Whether people already have build up a career or a family might be important for some because they have something to hold onto, but others in contrast feel that their illness is demolishing what they have built up so far. Hence, the age of a person does not help us understand how a person experiences his or her condition.

4.2.2. Gender

The gender of a person may shape the illness experience. Koch *et al*. argue that little attention is paid to gender differences with regards to the experience of Multiple Sclerosis and especially of incontinence (2000: 254). McCabe *et al*. analyzed gender differences with regards to coping and state that women are more likely to use coping strategies which involve looking for social support and that they were focusing more on the positives than men. But aside from this, the authors did not discover any differences in the coping strategies used by men and women (2004: 360). Another aspect worth investigating is social context: in a situation where a woman is supposed to stay at home and look after the children and the man has to provide the income, chronic illness resulting in unemployment and dependence can have a different meaning for men and women. Thus, when a man is unable to work and cannot provide money for his family he may experience loss of status, whereas for a woman who cannot work anymore the consequences with regards to status loss might be less invasive (Robinson 1988: 62).

During my fieldwork, the only gender difference I discovered is that men seem to have more difficulties being in a wheelchair, perhaps because men are seen as strong and independent, while women are seen as weak and dependent. Men may associate being in a wheelchair with weakness and dependence, involving a subsequent loss of reputation. The fact that no more gender differences did surface might be a result of my small sample. Both men and women expressed difficulties keeping up their role as a parent and both genders had an issue with not being able to work anymore. But, partly, both men and women talked very openly and both genders were represented in all illness narratives categories. However, I did not talk to a woman whose illness narrative was extremely negative. But I would ascribe this rather to chance than to a gender difference.

4.2.3. Functional Disability

Multiple Sclerosis can lead to functional disability. “Functional disability includes physical limitations in the ability to perform one’s usual roles and activities (Sater, 1981)” (Wineman 1990: 294). 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, Rabins, Brooks & O’Donell 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). Furthermore Lynch *et al*. point out that there is still a lot of controversy surrounding the relationship between depression and the patients’ grade of disability (2001: 411). In their study they found “no evidence of an interaction between disability and any of the psychological variables” (*ibid*.: 414).

Related to functional disability is the perceived uncertainty (*ibid*.: 413) of the illness. My informants had two types of Multiple Sclerosis, namely relapsing remitting and secondary progressive. With relapsing remitting the patient has unpredictable attacks which may result in permanent deficits and which are followed by a period of remission. With this type the perceived uncertainty is larger, as the person with Multiple Sclerosis never knows when the next attack will happen and whether it will leave permanent damage. Secondary progressive is a form that follows after a period of relapsing remitting. The illness slowly progresses without any attacks or remissions. In my sample I did not observe differences in the illness experience between these two types. People with relapsing remitting and secondary progressive Multiple Sclerosis were represented in all there categories of illness narratives.

During my fieldwork I did not find a connection between the severity of the illness and the illness experience. However it has to be taken into consideration that I mostly talked to people who had a rather benign form of the illness. Furthermore, the people participating in my research are not representative of all people with Multiple Sclerosis, because people who experience many difficulties probably did not participate in my study. Still my informants represented a broad range, from very mild symptoms to severe disablement. Sarah (57), Andrew (59) (whom I did not introduce earlier but whose illness narrative belong to the category of normalization) and Patrick (49) use an electronic wheelchair but they are very positive about their situation and report that they have a good quality of life. In contrast Sean (24), Richard (38), and other informants I did not introduce earlier have relatively mild symptoms but in general their narratives all belong to the category of loss. They are all still able to walk relatively well, but they experience many problems with their illness and have difficulty dealing with it. To conclude, the severity of the illness in itself does not help to better understand how people experience their illness.

4.2.4. Dependence

Functional disability can lead to dependence. For some informants it is very important not to depend on others. In the Western world independence is a key value that is associated with ability, masculinity, leadership, and individualism. Dependence, in contrast, has negative connotations and is associated with weakness, femininity, indecision, egoism, and helplessness (Robinson 1988: 62). Moreover dependence can have consequences for the financial situation of the person and the fulfillment of social roles (Jones *et al*. 1984: 265). It could be that a husband, because of the illness of his wife, has to look after the children and adopt tasks in the household. This can lead to ‘unilateral dependence’ (Kelley, in Jones *et al*. 1984: 264), since one partner is more dependent than the other.

Due to the negative connotations of dependence some informants tried to do as many things by themselves as possible, even if it takes them a lot of effort. Caitlin (57) insists on still doing the groceries herself although her son or husband would do it for her. Alex (55) similarly still wants to do garden work, although his wife wishes he would not. Yet for him it is important to do it as long as possible even if it is tiring. Richard (38) and Peter (50) also have difficulties asking for help and prefer not to depend on others. Other informants expressed that they felt obliged to say ‘thank you’ all the time and be grateful because they feared that people otherwise would not help them.

People, however, who were already greatly dependent on the help of others and on caretakers, seemed to haven gotten used to the situation. Sarah (57) and Patrick (49) report that they lead a happy life. Emily (52), who to a lesser degree depends on people, expresses that people are really helpful and that there is always someone who is happy to help her. In summary, one cannot say that the more people are dependent, the more problems people experience. It is rather their way of dealing with the situation and thinking about it that counts.

4.2.5. Visibility

Visibility can play an important role in the illness experience. The more visible a condition is the more people are at risk of being stigmatized (Jones *et al*. 1984: 29). Indeed a lot of people initially express difficulties with using a walking stick or wheelchair. Emily (52) for example says: “When I was diagnosed I was very frightened, very frightened of the wheelchair and I went to the counselor and she said that I would be the same person in the wheelchair and that was very good”. Others felt more vulnerable and feared that they were the object of conversation. “If there is one thing I could change, that would be it, to fix the leg. So that nobody would see it and nobody would ask. Even though you might have inner problems, nobody would know. So you look just like a normal person” states Richard (38). Connor (59) feels that his disability overshadows him and that people just notice the wheelchair and do not see him as a person. He personally finds it unimportant how he dresses. But his sister disagrees and underscores that now his appearance is even more important, since he draws more attention towards himself. While telling me this, Connor realizes that when he stayed in the MS care center for a week there was a man with wild and uncombed hair. To Connor he gave the impression of being a lunatic. But some days later the man got his hair cut and Connor comprehended that his outward appearance resulted from the fact that the man could not comb his hair. He comes to the understanding that the outward appearance of a person can strongly shape how the person is perceived. Hence for people with Multiple Sclerosis it might be extra important to appear well looked after to counteract possible stigmatization. Although other informants mentioned that they are lucky that their illness is not visible because they suffer mostly from fatigue, this also brings along problems as they receive less understanding from people in their social surroundings.

Yet, other informants expressed that people are more friendly and helpful to them when they are in a wheelchair, as their illness is visible. Those people state they do not have problems with the fact that their illness is visible. In special situations some informants emphasized their condition and pretended to be more disabled than they actually are. For instance when using a disabled car park they would limp more than necessary in order to show that they deserve it. To draw a conclusion, most informants expressed that they preferred their illness not to be visible, but once their illness is visible some informants are adapting well to their situation while others are not.

4.3. Spirituality

The relationship between religion and health and disease is complex. Scholars for many decades discussed whether religion has a positive or negative impact on the experience of illness. In beginning of the 19th century religion was mostly seen as contributing to mental illness rather than helping people deal with their condition. Mostly based on practical experience, doctors and psychiatrists stated that the less religious people, were the more emotionally healthy they tended to be (in Koenig *et al*. 2001: 353). More recent studies, however, state that “religious involvement is associated with greater wellbeing and life satisfaction, greater purpose and meaning in life, greater hope and optimism, less anxiety and depression, more stable marriages, and lower rates of substance abuse” (*ibid*.: 256).

Following this positive approach, Idler identifies three ways of studying the relationship between religion and health. First, religion can, following Durkheim’s line of thought, be seen as beneficial to health because it provides support and social cohesion (Idler 1995: 684). Second, people suffering from a disease often turn to religion in order to find support. The community of a church and the assurance that divine authorities guard human life can help people to better deal with their illness. Third, because religion focuses on the spiritual and non-physical aspects of the self, it can help people suffering from a physical disease to judge their health situation in a more positive way (*ibid*.: 686). On the other hand, however, religion can also have negative effects on health for example when illness is seen as a punishment from God. This view can create feelings of sinfulness, guilt, and responsibility (Fallot 2001: 112).

Deconstructing Christian theology, scholars have detected problems with regards to chronic illness and disability. Although people with a chronic illness may experience relief by turning to religious authorities or places, chronic illness cannot be cured. This leaves uncured people excluded and in the worst case, blamed for their condition (Williams 1993: 85). Therefore, Williams brings forward the argument that chronic illness needs new interpretative schemes with regards to religious systems of meaning. A similar picture arises with regards to disability. Reflecting on the Christian theology reveals that healing, wholeness, and holiness are problematic in the context of disability (Berinyuu 2004: 205). Christian theology is centered on perfection and ideal types, but people with a chronic illness or disability, in the opinion of some, do not live up to these ideals. In addition, disability is treated as a flaw which needs to be repaired.

Kleinman argues that the Christian religion adds a positive dimension to suffering, because the suffering body is seen as the concourse of the human and divine (Kleinman 1997: 322). Yet, Kleinman stresses that in Western society, suffering is more and more seen as something that needs to be avoided and prevented through technology and medicine. The redeeming character that suffering had in Christian theology has been lost (*ibid.*: 323). The question that rises is how people experience their sick body when suffering in society on the one hand is seen as something that has to be avoided, but in Christianity is seen as a means of purification (Turner 1984: 67).

Scholars make a difference between spirituality, religion and religiousness (Gordon 2002: 164). For the purposes of my study I analyze whether any form of spirituality, including religion, coupled with attributing meaning, helps people to better deal with their condition. For Emily (52) whose illness narrative describes posttraumatic growth, belief plays an important role. She describes herself as very spiritual and thinks that her illness is a “grace of God”.

> Yes, I am very spiritual. I did go to mass yesterday. I really believe. And I see it all around me. In the sense that I believe God puts people on my path, I really believe that God provides me with everything I need.

She believes that there was a reason why she got Multiple Sclerosis. Because of her illness she changed her priorities and became a different person. In her eyes, God would not give her anything with which she could not cope. Her belief helped her give meaning to her illness and see it in a positive light. Peter (50) whose illness narrative is characterized by normalization, emphasizes that he is not religious but that he believes in a spiritual entity. He describes his belief as a combination of Native American beliefs, ancient Celtic beliefs and Buddhism. However, he strictly distances himself from the Roman Catholic Church, which his parents and family belong to. His parents believe that if he returned to the church and prayed more, he would feel better and his symptoms would ease. An aunt goes so far to state that he got Multiple Sclerosis because he is gay and God disapproves of this. In reaction to his family’s belief he states that “God won’t push my wheelchair” and therefore would not help him. But his combined beliefs help him to keep a positive attitude towards life and not to give up. Patrick (49), similarly, states that his illness had an important lesson for him, namely to give up his perfectionism. He got his inspiration from several self-help and New Age books. As he believes in mind over matter he thinks that if he had more discipline (for instance, if he meditated more) he would improve physically. Interestingly, this sense of untapped control seems to empower him rather than discourage him.

Alex (55) thinks that his illness was necessary for him to change his lifestyle and personality. His illness, thus, has a special meaning for him. Since Alex gives his illness a positive meaning he is better able to deal with it and experiences it in a positive way. Jacqueline (50) who has to use a wheelchair is not religious but expresses that her illness took the pressure of her to do well and become outstanding. “MS gave me a reason not to be bothered [whether I do well or not] and to do what I like to do”. In that sense she gave meaning to her illness which had a positive effect on her.

What these people have in common is that their belief helps them to deal with their situation. The community of the church or another spiritual group does not seem to be of great importance. More important is that the people have the impression they are supported by a divine authority and that everything has a meaning. Giving positive meaning to one’s condition is also possible without being religious. In general the people I named are able to deal well with their illness. Thus, the ability to give meaning to one’s illness or to believe in a higher, protecting authority might contribute to a more positive experience of the illness.

However, several informants did not give meaning to their illness. Anna for example says: “No, I never go ‘God why me?’. I was surrounded by people who didn’t deserve what has happened to them. So why not me?”. Sarah shares this opinion. Andrew (59) similarly does not give meaning to his illness but is able to deal with it well. As a conclusion, giving meaning does not necessarily help people to deal better with their illness and to experience it in a more positive light. But people who do give meaning in general have a more favorable experience with their illness. Yet some non-religious informants, who saw their illness as pure chance, like Sean (24) and Richard (38), experienced more problems. Other people did not connect their illness with religion but thought they contributed to it by leading an unhealthy life. Over-working and an unhealthy diet were factors some informants mentioned as a possible explanation for why they got Multiple Sclerosis. Some people mentioned that their parents or people around them still associated illness still with sinful behavior, but they themselves did not believe that. It might be that in more rural parts of Ireland this belief is still present, but the people I interviewed in Dublin did not believe that their illness was, for example, a punishment from God. Furthermore, my informants did not feel excluded from the Catholic Church because of their disability. The fact that the Catholic Church concentrates on wholeness and healing left no informant disturbed or rejected.

Talking with two priests, a chaplain and a person who actively is involved in the service of the Catholic Church I learned that suffering is still seen as something positive, which brings you closer to God. Yet, my informants did not experience the redeeming character of suffering. Firstly, people preferred not to use the expression ‘suffer from MS’, and secondly people did not associate anything positive with suffering, but thought of it as something that has to be prevented. In general, one can conclude that religion did not have a negative effect on the respondents I talked to. Yet, how people interpret their illness can play a crucial role.

4.4. Conclusion

This chapter shows that all those different factors in themselves do not help to understand why people experience their illness so differently. Analyzing illness narratives in this semi-statistical way assumes that there is a direct relationship between one or two factors. But reality is more complex; although all 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 picture arising is thus inconsistent and differs for each individual. Tackling this problem by analyzing individual factors is therefore not very fruitful. However, what is obvious is that the relations between these factors and the impact they have differ for every person. This is not to say that those factors do not play a role; to a certain extent they all shape the illness experience, but their impact is not universal. To Anna family and friends are very important. To Alex family plays a smaller role in the illness experience, but his spiritual development is more prominent. Likewise, Emily deals with her situation through belief. Richard and Connor do not want their illness to be visible; on the other hand this does not worry Sarah and Emily anymore. This list could be endlessly continued, but my point is that there is no common factor which is equally important to all informants. In general, however, I would state that the perceived social support is important for most informants. Likewise, a combination of factors is insufficient to explain the differences in Multiple Sclerosis experiences and narratives. It is not the case that all people who experience posttraumatic growth or who strive for normalization have, for example, a strong social network and are still able to work. Contrarily, not all people who are not able to work anymore and who do not receive much support narrate an experience of loss. The same applies for the remaining factors.

With reference to resilience theories, one can criticize that its proponents all assume that a certain combination of factors can be found in order to explain why some people display resilient behavior and others do not. Depicting the correlation of certain factors in a statistical way insinuates that the correlations are similar for a diverse group of people who all experienced the same traumatic event. But my empirical examples show that different factors can have different importance for each individual. As adversity varies in form and impact an unending list of factors could be identified. Since this approach is problematic, in the next chapter I present an alternative way of analyzing the illness narratives. This approach focuses on a commonality – transformation – which all illness narratives display.

5. Multiple Sclerosis as a Transformative Experience

5.1. Rite of Passage and Liminality

Close readings of illness narratives reveal that it is impossible to find one or two single factors that determine how people experience their illness. As each individual situation is complex, searching for different factors that could explain differing illness experiences is not very fruitful. Even if such factors are found, one cannot assume a direct relationship between these factors and the illness experience. However, all illness narratives describe a form of transformation. It therefore seems appropriate to examine and describe the process of transformation instead of focusing on individual factors. In anthropology the concept of *rite de passage* describes a transformative event. Van Gennep firstly described different rites of passage like birth, initiation, marriage and death and demonstrates how they reproduce society. He divides rites of passage into three phases: separation, transition (liminality) and reintegration (1977 [1960]: 11). The phase of separation implicates the detachment of a person or group from his social position. While the old group is left behind, the individual or group moves towards the unknown. Entering the liminal phase, the person experiences an ambiguous position and is isolated from society. The person completes the passage by reintegrating into society with a higher status (Turner 1967: 94; 1969: 97). According to Turner rites of passage are found in all societies but are more prevalent in small-scale societies. Those rites denote and exhibit the transition between states. He regards transition as a process and emphasizes that rituals are transformative (Turner 1967: 93 - 95). In contrast to van Gennep, who viewed rites as a descriptive fact, which affected or marked transition, Turner emphasizes that transformation is a major aspect of rites of passage (Kapferer 1984 [1979]: 5).

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 at once no longer classified and not yet classified” (Turner 1967: 96). He emphasizes that people in a liminal phase are considered as unclear and contradictory. Referring to Douglas (1966) he states that liminal people are regarded as dangerous because they are seen as ambiguous and unclean (*ibid*.: 97). Being in a liminal position is dangerous for the individual because he or she resides in a state of “social homelessness” (Eriksen 2001 [1995]: 138). The person does not know whether he or she can reintegrate into society. Society on the other hand, risks that the person will reject society's values and hierarchical structure (*ibid*.). Liminal beings are symbolically sexless and have no status, rank or any characteristics that would distinguish them from their fellows (Turner 1967: 98).

Until now only negative aspects of liminality have been described, but Turner also pays attention to positive characteristics. "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. People who are in the liminal phase often have to display complete authority and submission to their instructors. However, toward their fellows they demonstrate total equality (*ibid*.: 105, 99). Turner introduces the concept of *communitas* to describe an unstructured and undifferentiated community among people going through a liminal phase (Turner 1969: 96). In the *communitas* people experience a state of oneness with others; "a feeling of unity beyond all categories and hierarchies" (Peters 1994: 6).

Rites of passage have traditionally been analyzed in small-scale societies and some scholars doubt whether they can be applied to describe phenomena in modern society (see Barrett 1998: 479). However, 'rites of passage' can still be useful as a dynamic framework for analyzing social reality, especially the phenomena of social transition and transformation (Froggatt 1997: 126). With regards to disability, Murphy *et al*. applied the concept of liminality to describe the situation of people with a disability and especially people in a wheelchair. They state that people in a wheelchair are at the margin of society. According to them, disability is an "in-between state for the person is neither sick nor well" (Murphy *et al*. 1988: 237 - 238). In line with Douglas who argues that everything which cannot be categorized is perceived as polluted and subject to taboo, Murphy *et al*. argue that people in a wheelchair can be seen as a "conceptual anomaly" (*ibid*.: 239). 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).

Similarly, scholars apply the concept of liminality to describe the experiences of chronic illness and cancer. Navon and Morag show that people experience different reactions to hormonal treatment of prostate cancer, and some deal more positively with their illness than others. They 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).

Often studies which apply the concept of liminality to describe the situation of people with a chronic illness or disability sketch a rather negative picture. Murphy *et al.* are rather pessimistic about the situation of people in a wheelchair: "Millions of disabled people lead an almost cloistered existence, detached from the mainstream of society by loss of communicative functions […] or by loss of mobility, as in the case of paralytics" (*ibid.*: 237). Furthermore they argue that people with a disability are isolated because 'normal people' consider them suspect and opaque. Duval, who writes about people with Multiple Sclerosis, states that disabled people occupy the margins of society and experience a deficit in their quality of life (Duval 1984: 635). Barrett describes the situation of people suffering from Multiple Sclerosis in a similar way. She adds that in capitalist societies that have developed medical technologies people who cannot be cured are considered anomalous and form an isolated group. Moreover, she argues that the capitalist societies are not adapted to the needs of people with a disability or chronic illness. This pushes them into a liminal position (Barrett, J. 1995: 161). An extreme statement comes from Deegan (1975), who suggests that the liminality of physically disabled people is only resolved by death (in Barrett 1998: 481). To an extent these scholars' descriptions may still be applicable, but one can argue that in the twenty years since Murphy *et al.* published their article, many things have changed for people with a disability.

Harrison and Kahn, in contrast to Murphy *et al.*, apply not only concepts of liminality, but also rites of passage to people with a disability. They contend the assumption that those with a chronic illness or disability "remain in a liminal state without a transition and become permanently marginalized by the culture" (Harrison & Kahn 2003: 91). According to them people with a disability or chronic illness first go through a period of separation, for example when they have to stay in a hospital for medical research or when they cannot leave the house because of their symptoms. These people are thus detached from normal society and enter into a medical terrain. Then they go through a stage of liminality as they begin to realize that not only their bodies have changed, but also their position in society. "The realization of a change in physical state is followed by a state of ambiguity, and these persons may question their position within their culture" (*ibid.*: 90). These people may express decreased self-esteem, anger, and even rejection of their new identity as 'undesirable'. Furthermore, people residing in a liminal state experience a dissolving of gender, a loss of status and rank, and exclusion from the hierarchical structure of society. Losing their old status, as for instance breadwinner or housewife, they are uncertain about their futures. They are unable to categorize themselves as they are neither completely healthy nor completely sick.

According to Harrison and Kahn people with a disability or chronic illness can follow four different paths. First, if they are in contact with other people who have a disability who provide them with support and understanding, they can enter into a disability culture. To enter into a disability culture means spending most of one's time with people who have the same or similar condition. It also means comparing one's situation to that of other people with a chronic illness, rather than with the situations of 'normal' people. The second path is to overcome impairment and re-enter into the culture of origin as is the case for people who have beaten cancer or corrected their impairment through an operation. Often such individuals receive a higher status, as they have won the battle against the enemy. Third, people have the possibility of hiding their impairment and re-entering into society. They apply the strategy of passing, pretending that they are healthy, they are able to integrate with 'normal' people. The final option is to remain in the liminal phase and therefore in a marginal position (Harrison & Kahn 2003: 92). Although Harrison and Kahn contend the assumption that people with a disability must reside permanently in a liminal phase, they believe that people can leave liminality only by entering into a disability culture or by hiding the impairment. Neither they nor other scholars describe situations in which people with a disability or chronic illness can reenter society and live normally, without hiding their condition, among healthy people.

Moss and Dyck also apply the concept of rite of passage to the experience of living with a chronic condition. However, they emphasize that a rite of passage with regards to chronic illness does not simply mark the transition between ill and healthy. Rather living with a chronic illness is a complex experience which fluctuates and changes from day to day. In their eyes, linking the concept of journey to the transformative experience makes more sense. This journey encompasses fluctuations, inconsistencies in the physical body, and a personal transformation (Moss & Dyck 1999: 158). Teather calls attention to the fact that those passages have a significant impact on a person's life and on his environment, and therefore demand personal skills in dealing with them. "Our passages, intensely personal, thread their way through, impact upon, and are influenced by the institutional fabric of social life: home, work, school, family, religion, nation, for example" (Teather 1999: 1).

In the following section I present the situations of various informants in order to illustrate how people go through a rite of passage and explore alternatives to ending up in liminality or in a disability culture. In contrast to scholars who only apply the concept of liminality or rite of passage in order to describe the situations of people with a disability, I want to use the concept in order to understand why some people experience their illness in a positive way, while others experience it in a negative way.

5.2. Residing in Liminality

5.2.1. Loss

The preceding theoretical discussion has shown that the concepts of rite of passage and liminality can be applied to the situations of people with a disability or chronic illness. Connor's (59) narrative meets the criteria of the liminal phase on an individual and social level. On an individual level he feels aged and alienated from his body. His fear is that his illness is taking over his identity. He is less motivated to undertake activities because they cost him too much energy. In other words, he has lost his ambition in life. His liminality is demonstrated by the fact that he does not consider himself healthy, nor would he call himself disabled. On a social level his liminality becomes even more obvious. He has the impression that people look at him differently and perceive him more and more as 'the fellow in the wheelchair'. He feels bad when he has to ask for help while in his wheelchair, because in his opinion most people are uncertain how to behave. This results in awkward situations. The uncertainty of the other people is probably due to their inability to classify him or judge his position.

Moreover, Multiple Sclerosis affects Connor's role as a father. Since he can hardly move without a wheelchair and recently lost his car in an accident, he has become more dependent on his two sons. Connor states that his illness puts a strain on this relationship. According to him, small tasks like shopping for groceries can turn into 'family sagas'. For example, when he asks his son to shop for him, his son often procrastinates. As Connor does not want to wait, he tries to go to the shop himself. Yet this task is too exhausting for him. Feeling guilty that he did not help sooner, his son then follows Connor to the store. Connor also feels guilty because he depends on his son in a way that he feels to be inappropriate. His illness, thus, shifts the role allocation in his family.

As Connor can only work part-time, his illness affects his status and authority, both in his eyes and in society's. He feels he has become dependent on people and cannot express his opinion or true feelings anymore, because people might refuse to help him:

> For survival purposes you can’t complain. You’d be isolated because people will find it very easy… you are giving them a reason. You almost have an obligation to be cheerful and to project a kind of serenity that you are feeling something else and you just don’t feel serene.

Since Connor has the impression that ‘nobody likes a grumpy cripple’ he thinks that he has to pretend to be grateful and content. He feels he cannot speak his mind, and increasingly loses his old identity. He points out that if he asks something of people they will suggest that he do it differently and then he has no choice but to accept their way of doing it. This leaves him helpless and dependent and increases his feelings of having lost his old status and identity. Not only his career, but also his leisure activities have been curtailed. He is no longer able to pursue his interests as an amateur actor, cannot go out for a drink and experiences less pleasure in activities with his friends:

> They ring you up and ask if you want to go for a walk, they would push the chair. You say yes even if that’s the last thing on the world that you want to do. I don’t want to do it. I don’t want to hear a voice from behind…so you go with it but you might not want to.

Moreover, Connor has not found a group of new friends yet and does not want to identify himself with other people who have Multiple Sclerosis. About a meeting of other men with the same illness he states: “I thought here I am, we all have MS, but we have nothing else in common…I am sitting here with a holocaust denier”. His illness left him feeling very isolated.

However, I have to add that when I met Connor for the last time about two month after our initial meeting, he told me that he had asked for an electronic wheelchair, against which he resisted in the beginning. Now he has realized that it gives him more freedom and independence because he can move on his own. Also, he has been away on a weekend organized by the MS Society. He still has difficulties seeing people that are worse off than him because he has the impression that in a few years he will be in their position. Yet he also enjoyed the weekend. Connor’s situation shows that he is ‘betwixt and between’ two worlds. He cannot keep up anymore with his old life but does not want to associate himself yet with the disability world.

Another informant who resides in a phase of liminality is Sean. He is only twenty-four years old and was diagnosed just after he finished school. He has relatively mild symptoms but those affect him greatly because he is not able to do the things he did in the past. He cannot participate in rugby or other sports anymore. Moreover going out with his friends is very exhausting, and drinking one or two glasses of beer impairs his sense of balance to such an extent that he has problems walking. Sean experiences many problems with his illness and is depressed about the situation. He has the feeling that he cannot realize his dreams anymore. He tells me that he would like to travel around the world but because he has to take an injection every month this is impossible. He has the impression that now that he has Multiple Sclerosis, he is strictly limited in the things he can do. It frightens him that he does not know how bad his illness will become. This uncertainty concerns him every day.

Sean tries to keep up with his friends but does not really succeed. “I am just being stupid, I think, really being stupid. I try to keep up with my friends as much as I can. But I can’t…it’s stupid stuff”. Although his friends know that he has Multiple Sclerosis they do not fully realize what this means for him. “If I drink, if I had two drinks my balance is just way off and all my friends would joke, you’re so drunk, you’re so drunk. But I am not…I don’t know what to say about having MS, all I can say really is that it sucks. It sucks, but what can you do?”. The way he said this showed that he was hurt by the fact that his friends did not understand him. In general he often feels misunderstood by people around him. “People think I am lazy all the time, but it’s not my fault. I hate when people say, you don’t look sick. It’s just the worst thing you can say”. Thus, on the one hand Sean still wants to continue with his old life and avoid the label of ‘disabled’, but on the other hand he is longing for acceptance and recognition.

In a conversation I had alone with his older sister it became obvious that he does not talk much about his illness. His sister depicted his situation more positively than he would. For example, she emphasized that her brother still goes out a lot, although it might exhaust him. She underlined that he still goes jogging and participates in certain kinds of sports. Sean, in contrast, told me that he cannot continue going out with his friends. Furthermore it was a huge shock for him when he discovered that he could not go jogging anymore because it was too tiring. Thus, he keeps many concerns to himself and pretends to the outside world that he experiences fewer problems with his illness than he actually does. This leaves him isolated with his condition. In addition, he stressed that he was very happy to talk to me because he had not talked to anybody about his illness so openly.

To summarize, Sean’s narrative is characterized by various aspects which resemble the liminal state. First he is uncertain about the future, second he experiences a loss of status, because he cannot be who he would like to be, nor do what he would like to do. At the moment he is unemployed because his old job is too demanding physically. As he is dependent on medicine he cannot use his ‘free time’ to travel either. Hence, the status people of his age would normally acquire by traveling or working is out of reach for him. Furthermore he is in an ambiguous situation because on the one hand he unsuccessfully attempts to come across as healthy and keep up with the lifestyle of his friends, but on the other hand he does not want to associate himself with people who have a disability. This leaves him betwixt and between his old life, which he can no longer pursue, and a new life, which requires adaptations he does not want to accept yet.

Residing in a state of liminality is mainly characterized by being torn between two worlds. The person stands with a “foot in two different worlds – a healthy world and a world of illness” (Myers 2004: 265). As those examples show people still try to continue with their old life and try to keep up with their friends but do not succeed. Yet, they have not made new friends or gained a new valid status within their old social network. They often experience a status loss that they are unable to compensate for, because they lose their work or can no longer participate in activities like sports or going out. Their status is also ambiguous to the people around them, who do not know whether they are sick or healthy. They are afraid that their disability will overshadow their personality. For some reason these people are not able to pass through the phase of liminality. “Failure to make a successful passage results in a prolongation of liminality” (Schouten 1991: 421). However, this does not mean that they will remain in a liminal phase for the rest of their lives. The case of Connor illustrates how he is increasingly getting in touch with people from the MS society and accepts using an electronic wheelchair with which he earlier did not want to be associated. Similarly, Sean states that in comparison to last year his attitude towards his illness has slightly improved and expresses that he will try to deal differently with his illness in the future.

The narratives of all people who reside in liminality belong to the category of loss. One can thus conclude that applying the concept of liminality to people with Multiple Sclerosis illuminates the conditions of people experiencing loss. Later in this chapter, I try to answer the question why those people for the moment reside in liminality.

5.3. Transcending liminality

5.3.1. Normalization

5.3.1.1. Association

In this section I discuss different ways through which people can leave the liminal phase. One possible route is through normalization. For example, Peter (50) passed through a phase of liminality and then reentered society. He has been diagnosed seven years ago and his life changed dramatically because of his illness. The following quote describes how he reacted to the diagnosis and which effects Multiple Sclerosis had for him.

> My social life before I was diagnosed has mainly disappeared; mostly because of my fatigue. In that respect my life changed drastically. It was a matter for depression also. Also my work, I didn't lose my job: I was told to resign. My job was so important to me. I was working 14-16 hours a day and then it was gone. That was difficult and I had to stop driving, it is not save for me to drive. I think almost every part of my life has been affected. I lost many friends because of it. I found that in any group of people many say they are friends, but when something happens they disappear and I did lose many friends. I have more contact with family members. In fact I meet my parents once or twice a week. Yeah, a big change in my life. The problem was how to cope with it. Like I said I was depressed in the beginning. And one night I was sitting at home listening to music and I was getting more depressed and then I thought 'stop, I have to get on'. Not sit in a corner and rot away. The next day I made myself go out, to a supermarket and I felt very embarrassed, because I had a walking stick and people could see me with a walking stick. That was difficult. Now I don't worry about them anymore. A big thing would be the fatigue. I met you at the road and just walked a few meters and now I am tired. In the beginning I used to get upset with it. I hated to do it. I hated to do it. But now I train myself to say, maybe tomorrow; even if it is important. I have learned that nothing is so important, it can wait.

This quote illustrates how Peter transformed from being a depressed person to being someone who accepts his illness and copes with it. These three critical months can be seen as a phase of liminality. Peter probably resided in a liminal phase when he had the first symptoms and did not know what was going on. He reports that he thought he was going crazy and suspected that he might have Alzheimer's disease or something similar. Moreover, Peter was very isolated because he had lost many friends. With some friends he simply could not keep up, others were afraid that Multiple Sclerosis was contagious and left him. Consequently, and as a result of losing his job Peter spent a lot of time in front of the television, switching it on when he woke up in the morning and switching it off when he went to bed. He states that he was depressed at this time and his life did not make much sense to him. But he also describes a turning point in his life: the decision to approach his situation in a more positive way.

In Peter's illness narrative, adapting and returning to the normal are the foremost themes. Peter feels that his illness affects his body, but not necessarily his personality. His transformation is directed towards returning to his old life as much as possible. He needed to make some adaptations in order to do so, but one could say he has found his way back to society. In his eyes he has a clear position in society and does not feel that he is in an ambiguous position. By not blaming things on his illness and trying to keep a positive attitude, he relegates his illness to the background. Although he is in contact with other people who have Multiple Sclerosis, his reference group still seems to be healthy people. He distances himself of people who are very focused on their illness, blame everything on it and give up easily. Therefore one can say that he has left liminality without entering into a disability culture and disassociating himself from 'normal' people. His narrative shows that having a chronic illness does not necessarily mean that one is either stuck in liminality or has to disassociate oneself from one's original social group and entrance into a disability culture.

Patrick (49) is another person who was able to transcend the liminality he resided in. He was diagnosed when he was twenty-four years old, but back then the effects of his illness were minimal and he was able to work as a solicitor. After a few years he went to the North of Ireland to work there, but because he neglected his health his illness progressed faster and he became unable to work. His illness also affected his social activities. One can argue that from this point on, he increasingly resided in a liminal state.

> As it got worse, when I couldn't go out for the weekend, because I couldn't stand that long and then to go to discos and nightclubs and chasing girls and before I was afraid of girls… And when they [his friends] stayed away and I felt very angry with them. I was very bitter for a while. Thinking how they could do it to me and if it was someone of them I would say, come on, come on, we are going somewhere where you can sit down. Maybe they were jealous because I got all the girls. That must have been it [laughs].

His way of talking about this shows that now he is more accepting his situation. For some time, however, Patrick resided in a liminal phase. Stopping his work was as a solicitor was a large status loss and disappointment for him. He could only proofread documents, which in his eyes was a very boring task. Second, though he tried to find friends who also have Multiple Sclerosis to replace his former friends, who were not very considerate of him, he thought that apart from the illness they did not have much in common.

Patrick states that back then he was feeling depressed and sorry for himself. It was hard for him to accept that his parents sent him to a nursing home because they were too old to take care of him. Now, however, he is in a different nursing home which he prefers and where he has found friends. By reading self-help books and talking to friends he gained new inspiration. He believes that his MS was sent to teach him to let go of control, because he was too much of a perfectionist. Hence, at a certain point he decided, inspired by books such as ‘The Power of Now’ by Eckhart Tolle and ‘You Can Heal Your Life’ by Louise Hay and by certain friends to change his attitude and outlook on life.

> All the books I have read and all the stuff I had in my mind, I had to put into practice and I did…totally accepting your life situation, making friends with your life situation, making friends with everything, instead of life making your enemy. Life could only be your friend if you make friends with it. There were young carers, young attractive people and they liked me and they were talking to me. And I thought there will never be a romance. I just got on so well with them, because they thought I am much younger than I am.

From these books he gained new confidence, which made him in his perspective more attractive to women. Patrick talks a lot about the relationships he had with women and emphasizes that he now is together with someone who does not have Multiple Sclerosis. This is very important to him, as it in his eyes proves that he is still attractive and has success with the other sex. Patrick believes that one day there will be a cure for his condition. He had assumed that in the year 2000 he would not have to be in a wheelchair anymore and was disappointed when this was not the case. Because he thinks that there will be a cure one day, he does not really want to do active physiotherapy. He has the impression that at the moment it does not help him much, but he wants to give his all when a cure is developed. In that sense Patrick lives in a constant state of ‘false’ hope, as in his lifetime there probably will not be a cure that will get him out of his wheelchair. Furthermore, he believes that if he meditated more and used more positive affirmations he could improve his physical state. But he states that he does not have enough discipline to do so. Again, this gives him a false sense of control over the situation. It does not seem to depress him that he does not have the discipline; on the contrary he seems glad that theoretically, he has the possibility of improving his condition.

5.3.1.2. Disassociation

Caitlin (57) was diagnosed in 1988 and after a brain tumor has to use a wheelchair. She is able to transcend liminality by being active in the MS society and the Irish Wheelchair Association. Sharing experiences with people who have the same or a similar condition helps her dealing with the situation.

> That’s why I like the MS meetings, you can go there and say, ‘God, such a rotten week, I’ve had’. It is really, they are great characters. I can relate well to them. Whereas before I didn’t want to know anybody who had MS, but now I enjoy the meetings. It is very therapeutic because you can relate to them better than to a normal person.

She underlines that there she can moan and complain which helps her getting weight off her shoulder. Another advantage which she mentions is that she does not have to dress up for those meetings but can come the way she is: wearing a jogging outfit and with messy hair.

In contrast to the benefits she experiences through contact with her peers, she perceives many difficulties in contact with ‘normal’ people. Because of her symptoms the spontaneous element of her life is gone. She cannot just go out when she likes to. When her husband would announce he had invited friends for dinner, she would ‘freak out’. She also does not like noisy social situations, such as groups in pubs, because she cannot follow the conversations. This is another reason why she has broken off contact with her work colleagues and some friends. She had the feeling that she could not keep up with them anymore and she did not want to come across as disabled.

> Well, I sort of cut myself off for a while. It took a year or two to go to the MS thing. I have pre-MS friends and I have new ones and mostly my friends now would have MS. Okay very old friends, I grew up with, they knew I have MS and talk about it. But my working friends, I never told them. I couldn’t keep up with them socially. They were drinkers; those were good times and it was a bit of a wild social scene. So I couldn’t go back to that. They were good friends too, but I couldn’t bring myself to having to go out with a stick and all that kind of things. So I sort of made a new set of friends. I just cut myself off and I am sorry, looking back now, I am sorry because I had really good friends and I liked them and that.

This quote demonstrates how Caitlin went through a period of liminality where she was ‘betwixt and between’ her old life and a new life that she had not yet begun. While she has exited liminality with regards to her friends, the situation with her family is different. In the first two interviews she described that her illness is putting a strain on the relationship with her husband. “The relationship with my husband is very fraught. He is sitting down there and he is watching me struggling and he never would say, ‘can I help you’. [Addressing her husband] Why you always help me when I don’t need help”. According to her he does not help her when she needs it. But when she wants to do things on her own, for example, shop for the groceries, he does not let her. When I interviewed both her and her husband, these tensions became obvious. When I asked him about his wife’s symptoms, he mostly mentioned mental problems like a lack of concentration and forgetfulness. He furthermore stated that his wife should not use the wheelchair all the time, but try to move around in the house without it. Caitlin told me that she goes to the gym every day in order to build up her physical strength. Though her husband acknowledges some aspects of her illness, he does not seem to fully understand others. However, this impression could be due to a bias. As I have spent more time with Caitlin I might tend to take her side.

Moreover her son does not seem to have accepted that his mother has Multiple Sclerosis.

> Then he says, ‘you are not really sick, are you?’ And then I say, ‘I am only pretending’. Then he said, ‘I am getting fed up with you, everything is about you, you, you’ and I say ‘yeah, well I said yes it is at the moment’. But it is true, when somebody is sick in the house it really is all them. That’s what I don’t like about it.

Caitlin’s illness narrative describes a transformation. It illustrates that living with a chronic and progressive condition means adapting constantly to new situations and trying to accept them. This transformation runs throughout different episodes in her illness experience, which are characterized by different emotions. The first episode describes the period before she got diagnosed. With sentiment she thinks back at the time where she had a good social life and many friends. After her diagnosis, a lot of things changed for her and she broke off contact with a lot of her friends. This period was very difficult for her. After a few years of coming to terms with her illness and finding new friends, she accepted her situation and led a relatively normal life. However, after her brain tumor her symptoms worsened and she had to stop working and move away from her old house because she could not climb the stairs anymore. Her way out of liminality is by associating herself with other people who have disabilities. One can argue, however, that with regards to her family she still remains in a liminal phase.

5.3.2. Posttraumatic Growth

Deconstructing Emily’s (52) illness narrative illustrates a clear transformation from experiencing many difficulties with her condition to experiencing posttraumatic growth. For short distances she can still use a walking frame and only has to use the wheelchair for longer distances. 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 results 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 Emily. Her active social life and the extremely strong support of her friends make it easier to deal with the situation. Her friends would even go so far as to joke that ‘the cripple gets all the attention’. Emily thinks that, on the one hand it is good that her friends are able to joke about it, although on the other hand her dependence can be hard for her. 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.

What struck me in the interviews I had with Emily is that she 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. Emily is very spiritual and believes that God only inflicts something on her with which she could deal.

> I suppose I believe that God wouldn’t give me anything I can’t cope with, I trust in God and I would ask for things…I have everything I need. I believe that everything I need will be provided for me.

Thus, her belief helps her to deal with the situation. 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. 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.

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 is wife, his children, and his work colleagues. Hence, Samuel sees his illness as a wake-up call which transformed him for the better. 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.

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.

Another person who went through a similar transformation is Alex (55). Especially the time before the diagnosis was very hard for him 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. Before this change, Alex was a very active person. His work as a chef was very important for him. He represented Ireland at the World Culinary Olympics and won a silver medal and was the caterer for a former minister.

> 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 actively decided to change his outlook on life. He did not want to accept his fate, but challenged it and transformed his illness experience into personal growth.

> 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 to see what is out there. I find things can be very good, like the brain gym…it enhances your wellbeing, believe it or not.

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. It is hard for him that he is not able to do some things anymore, but it is important for him to at least try. Moreover, 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 wrong which he strives for at work and with 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 how 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. I don't want to be felt sorry about.

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.

What all these informants have in common is that they experience a positive transformation. They all experienced liminality with regards to their illness. Yet, they seem to have used the experience of liminality as a space for reflection about their life (Turner 1967: 99). Another striking commonality is that they all state that before they were diagnosed they led an unhappy life. As memory is constructive, it is the question whether they would have expressed the same opinion if I had interviewed them before their diagnosis. From their perspective, their lives appeared perfect to the outside world, but were miserable inside. Maybe they experienced a positive transformation because in some way they were unhappy with their old lives and needed something in their lives in order to change.

As the above demonstrates, there are different paths to transcending liminality. Either by entering into a disability culture, by striving for normalization, or by creating personal growth, people are able to leave the liminal phase and reintegrate into society. In doing so, they gain a new status. As Terence Turner (1977) points out gaining a new status does not mean that the old one has completely vanished (in Kapferer 1984 [1979]: 5). People who normalized their illness after passing through liminality have reclaimed their old status but have accepted that they are a person with a chronic illness. People who disassociate themselves from their old social group receive a new status, as their illness becomes an attribute which gives them access to a new social group. Likewise, informants who experience posttraumatic growth might appear to have lost status when they lost reputable jobs. Yet, their personal development has become more important and overshadows those aspects of their lives in which they are restricted.

As the empirical examples have shown, people use different path to transcend liminality. However, people do not necessarily transcend liminality in all areas of their lives. In the case of Emily she has transcended liminality with regards to her children, her partner, her friends, and at work. But with her parents and relatives she keeps an ambiguous status and does not have a clear identity. Similarly, Alex is able to have a clear status and identity at his work, but his friends are not able to categorize him and he keeps an ambiguous status. Caitlin has transcended her liminality with regards to her peers who also have Multiple Sclerosis or another disability, but still experiences problems with her family. Hence, transcending liminality can refer to an incomplete process, which nonetheless has an important effect if it occurs in significant areas of life.

These examples demonstrate that people with a chronic and disabling illness are not doomed to live at the margins of society. At the time of the study of Murphy *et al*. in 1988 this might have been true. Nowadays, however, people with a disability can easier reintegrate into society. In contrast to the four paths Harrison and Kahn (2003) propose, I argue that people with a disability do not either have to hide their condition, enter a disability culture or remain in liminality but can actually live with their condition among other non-disabled people. In that sense the concept of liminality has an advantage in that it is dynamic, implying a certain temporality rather than a permanent anomaly or ‘abnormality’ (Barrett 1998: 479). In the following I will analyze the findings of this chapter.

5.4. Discussion

In this chapter I have demonstrated that people who have been diagnosed with Multiple Sclerosis experience a transformation. Change is a part of human existence. Drastic changes can lead to social and personal collapse, but can also be a stimulus for personal growth and innovation. “Change can be rather smooth, continuous, and easy, or it may be sudden, drastic, and disruptive”

(Canda 1988: 205). Deconstructing how people transform after change, it becomes obvious that their transformations vary. While for some people illness is a negative transformation, for others it is a positive one. At a certain point some people, almost abruptly, decide to change, while for others the transformation is more gradual. Some people did change by themselves; others were inspired by books, religion or other people.

In contrast to scholars who argue that people with a disability remain in liminality or leave it solely through entrance into a disability culture, I hold that there are other options. By either normalization their illness or giving it a positive meaning, people are able to transcend liminality. A difficult and complex question arises form this observation: why are some people able to transcend the phase of liminality while others remain in it? This question is not meant to imply that those remaining in liminality will do so permanently, but it is certainly true that some people reside for long durations in a liminal phase. In the following I explore the concept of liminality more closely and first discuss why some people are able to leave this phase. Later I will attempt to address why some people remain there.

5.4.1. Why Do People Transcend Liminality?

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 [1979]: 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. Reflection can be described as “a meaning-making process that moves a learner from one experience into the next with deeper understanding of its relationships with and connections to other experiences and ideas” (Rodger 2002: 845). Reflection depends on a valuation of personal and intellectual growth. Further, community and interaction with others can foster reflection (*ibid.*: 845). 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). Hence, reflection can lead to a new evaluation of the situation and foster growth.

Hallstein applies the concept of liminality to hospitals, arguing that they are liminal spaces in which people can transform. According to her, 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).

Another way of interpreting the transformation in the illness experience is by focusing on turning points which, one could argue, especially happen during 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).

The narrative of Samuel (45) describes a clear turning point. He had his revelation while he was taking strong drugs in the hospital. The transformative character of liminality might explain why he changed his perception of the world and experienced a positive transformation. The isolation and uncertainty might have provided him with the necessary room to reflect on his way of seeing the world. Alex’s (55) illness narrative also depicts a turning point. His transformation started when he had to lay in bed for a long period of time and did not know what was going on with him. In this period he was isolated from his work colleagues and friends. During that time, when he states he was so low he considered committing suicide, he realized that he does not want to continue with his life as he had before. He wanted to broaden his horizon and make the most of his life. An important prerequisite of this realization was that he first acknowledged his reality and accepted it. From that point on his attitude towards life and his priorities changed. He saw a negative event, his illness, in a new light and used it in order to change his lifestyle. Hence it could be that people need to be isolated from their normal social group, experience ambiguities and hit rock bottom in order to transform.

Peter’s (50) story also describes a turning point in which he changed his life completely. He changed his attitude while reaching a bottom. Feeling depressed, having lost many of his friends, and watching television the whole day long, he actively decided that he did not want to continue with this lifestyle. Now he hardly watches television and tries to go for a small walk every day. His illness narrative also describes a turning point where he changed his life completely. Analyzing Patrick’s (49) narrative a similar turning point emerges. He had to reach a personal low before he transformed. In contrast to Peter, his reversal point was not a sudden realization. Rather he felt depressed and unhappy with his situation for a while, but gradually realized he did not want to continue in that vein. Step by step he accepted his disability, and with the help of friend and self-help books he reached a greater satisfaction with his life. His acceptance of the situation is a key aspect in his transformation. Like Samuel he now approaches life as something positive, and not as a struggle. Deconstructing Emily’s (52) narrative, the low point in her life is striking, as is her transformation. She described grief and overwhelming problems as a black hole, which she managed to crawl out of with the help of her friends and her belief in God.

In Caitlin’s (57) life one can also identify a phase in which she denied her illness and distanced herself from her friends. Over the years she increasingly accepted her condition. This might have been a period of reflection for her after which she decided to contact the MS society. Maybe she had to back out of the situation in order to accept her condition and assess her current capacities and incapacities. One could argue that, for her, the members of the MS society constitute what Turner calls *communitas*. In such a community, members all have an equal status and provide each other space in which to learn from other’s experience. Caitlin feels close to them, finds relief in complaining about her situation to an understanding audience, and does not feel disadvantaged as she sometimes feels in the outside world.

Analyzing the above narratives, it is striking that all describe a low period of being isolated from their normal social environments. 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 "'[f]alling 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'. The liminal phase should therefore not be seen as an entirely negative experience but also as a time that offers possibilities and opens up new paths.

Whether people use liminality as a space for reflection 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. Thus, 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 (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. Referring back to the second chapter, 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.

5.4.2. Why Do People Reside in Liminality?

In the following I will address why some people do not transform in a positive manner, but remain in a liminal phase. Analyzing the narratives of the respondents who reside in liminality, one gets the impression that they are overwhelmed by the problems caused by their illness. They do not take the time or do not have the energy to reflect on their situation. Richard's (38) life is very busy, and it seems that for the moment he just tries to keep his illness under control and is not willing to contemplate his situation. Connor (59) and Sean (24) might be about to begin to change, because they realize it is necessary in order to lead a happier life. In the end, only time will tell if they will be able to leave the liminal phase. Deconstructing their stories, it seems they lack protective factors in their lives. While all three have family and friends they seem to be unable to entrust themselves to others, which leaves them isolated. Moreover, the things that had been important for them, like sports, going out, or amateur acting, have been severely restricted by their illness. But they have not found alternatives yet. They are afraid that they might lose their jobs, as Sean already did, which would result in another status loss. Since they are not religious, they do not have a belief to hold onto. Another factor which negatively shapes their illness experience is their recent diagnoses. People who already struggle a lot dealing with their condition might not have the power, yet, to transform, because change takes energy. Moreover they might not trust in their own abilities and do not believe that their situation could improve. A lack of self confidence might explain why some people do not change. In the cases of my informants it might be that their illness assaulted their self confidence and they have not recovered from it yet.

Another possible explanation is that some people might prefer to keep to what they know, because they are afraid of the unknown. Thus, although they feel unhappy in the present situation, they prefer to live with the familiar. Those people might not be able to let go of their old lives and may not be open to change. Alternatively, some people may be resigned and lack the desire to change. One could argue that some people subconsciously want to get attention and therefore remain in a position in which others will pity them. However, with regards to my informants I had the impression they all wanted to live as independently as possible and underlined they did not want to be pitied.

Another way of approaching the problem is by focusing on cultural context. Society assumes that people with a chronic and disabling illness lead an undesirable life. People residing in liminality might act out societies' expectations of them. Since chronic illness and disability often are associated with isolation, dependence and unhappiness people might comply with this image. As a conclusion, it seems that people who do not exit the liminal phase do not use this period for reflection and transformation. One might argue that people are not able to use their agency to transcend their liminal position. In spite of their felt isolation, they might be caught up in the structure of social interactions, social relationships and society's expectations and can therefore not escape from their situation.

5.4.3. Importance of Rituals

A question that rises from this discussion is whether rites of passage can help people to better deal with their condition. Teather suggests that in our modern Western society, there might be "a latent need for certain rites (ceremonies) of passage to be reintroduced" (1999: 21). In her opinion, disability is a traumatic experience which requires social adjustments. Scholars often compare the modern Western world with tribal societies, which still have many rituals and rites of passages to guide people through life transitions (Peters 1994: 8). Kimball argues that as our society has either neglected rituals of transition, or that they have become so individualistic that they are experienced on the psychoanalyst's couch (1960: vxii, in Teather 1999: 21). Bernstein (1987) shares the same opinion and states that in our society, the patient has to use his own resources because there are no rites of passages (in Peters 1994: 8). People, thus, find themselves alone going through a difficult transition. Yet Teather stresses that rituals often are therapeutic and might help people dealing with the situation (*ibid*.: 21). According to Moore, ritual leadership, which could help people transform during liminal experiences, is missing in modern society (in Hallstein 1992: 249). Hallstein suggests that therapy can be a means to help people transform (*ibid*.).

Developing certain rituals that might help people to deal with their situation seems, therefore, to be a possibility. Although the use of rituals in therapy is not very common, different studies report a positive effect of therapeutic rituals (Jacobs 1989, Johnson 1995). A ritual can be defined as "a set of activities which encompasses basic rules to accomplish given tasks or goals in any social sphere" (Tribhuwan 1998: 16). Rituals encourage social cohesion since they communicate meaning shared by a group. They can help to resolve conflict and enhance the achievement of goals (*ibid.*: 17). Through rituals seemingly meaningless events receive new meaning: individual suffering, for example, can be interpreted as serving a higher goal or as means of becoming closer to Jesus. Due to those functions, rituals in traditional societies often are used for the healing of an individual or group. Healing rituals aim at the transformation of a person. Their intention is to provide self-acceptance and new insight for the person going through the ritual (Csordas 1983: 343). With regards to people with a chronic illness healing does not refer to successfully treating a condition, but to treating the whole person. Although the person's physical condition might stay the same people experience an improvement of their general feeling (Strathern & Steward 1999: 7). Jacobs illustrates how a healing ritual for women who have been abused helps them to reduce their fear, release anger, and improve their general mental health. In the ritual, the women first write down their traumatic experiences, read it out loud and then burn the paper. Then they write the name of their perpetrator on an egg and destroy the egg by throwing it against a wall. The last part is a guided meditation in which the women imagine themselves as goddesses (Jacobs 1989: 267).

Jacobs refers to Scheff (1979) and states that catharsis can be an important aspect of healing rituals. Catharsis consists of three elements which help a group of people undergoing transformation. First, people share their emotional distress, second they distance themselves emotionally, and third they observe how other people express their distress and discharge their emotions. 'Aesthetic distance' (Scheff 1979) indicates that the participant becomes emotionally engaged in the event but also remains a distant observer (Kirmayer 2004: 40). By keeping a distance people have the possibility to judge their experience differently. Social bonding, which creates a feeling of connectedness, is another crucial aspect of the ritual. The meditation aims at awakening trust in one's own capabilities (Jacobs 1989: 268).

Johnson *et al.* (1995) illustrate how rituals can help people suffering from posttraumatic stress disorder to experience relief. A central aspect of the ritual is catharsis which involves aesthetic distance. Thus people can go through their emotions without being overwhelmed by them. Further the ritual aims at establishing connections to the family or society. Such therapeutic rituals aim at re-contextualizing the traumatic experience and hence giving meaning to it (Johnson *et al.* 1995: 286-287). Individual suffering might be redefined as serving a higher purpose, thus assuaging its perceived meaninglessness.

Although the rituals described are for women who have been abused or people suffering from posttraumatic stress syndrome, certain elements can be valuable for people with Multiple Sclerosis as well. It could be important that people have a safe environment in which they can express their true feelings. Some of my informants mentioned that they cannot show how they feel as they are afraid that they will be rejected. In Ireland, as some people told me, personal issues such as illness are not often openly discussed. In such a context people could benefit from being provided with a space where they can express emotions like fear, anger and desperation. Through meditation people have the possibility to relax and retreat from their experience. Moreover, they have time to reflect about their situation and are encouraged to come up with new ideas and solutions to their problems. From a psychoanalytical point of view, during this time the unconscious self might provide symbolic solutions which after the ritual can be brought into practice (Hall 1991: 47, in Covington 1992: 489). By giving meaning to one's suffering and labeling it as something that opened up the possibility for growth people can allay their pain.

Receiving understanding from people who have undergone similar experiences can diminish feelings of isolation. It might be useful to involve family and friends at a later stage in the ritual, and thus reestablish the contact between the sick person and his or her community. The support people receive from the community and the encouragement to believe in their own abilities might be crucial factors of rituals that help people to transform their situation for the better. Achterberg argues that "through ritual one can gain access to the transpersonal forces of community and spirit" (1992: 162).

As a conclusion, although it might not be very common to use rituals in our Western society and some people might find it difficult to engage in them, I believe rituals can be a a valuable support for people. "Rituals heal because their purpose is to create social support and thereby decrease alienation, encouraging hope and faith which, in turn, reduce depression and anxiety (Frank 1979)" (Peters 1994: 7). Developing certain rituals for people who are diagnosed with a chronic and progressive illness may be an effective way of helping people to deal in a positive way with their condition. Rites of passage in which individuals are first separated from society and thereby have room for reflection, and then reintegrated into society with a new status, might be particularly appropriate. People do not necessarily need to experience posttraumatic growth in order to grow; normalizing one's illness can also be a way of growing and being better able to manage one's situation. On a practical level, the use of ritual might have the advantage that, in contrast to psychotherapy, the barrier to participate is smaller and the process is less time-consuming.

6. Conclusion

6.1. Reflection

In writing this thesis I struggled to find an answer to the second part of my research question: how can differences in the illness experience be explained? My topic is specific to a chronic and disabling illness, but the general question of why some people master a traumatic experience while others react with despair can be applied to other groups such as war refugees, sexual abuse victims, people thrown into poverty, survivors of natural disasters, etc. Psychological concepts such as resilience and posttraumatic growth have no equivalent concepts in Anthropology, and indeed I found few concepts with which to approach this question in that discipline. The framing of this complex question itself is problematic, because if the answer were simple, probably not so many people would struggle with their situation. Many factors play a role and it is debatable whether any one answer would apply to the situation of each individual with Multiple Sclerosis.

Although the historical focus in the literature on traumatic events has slowly shifted, from studying the negative effects to paying attention to positive sides, a predominantly negative focus remains. In the courses I took during my anthropological education dealing with traumatic events, no attention was paid to the experience of growth. Protective factors like religion were discussed, but only as coping mechanisms. In reviewing the literature for this thesis, I found scarce anthropological literature on the topic of chronic illness, and what was written, was mostly negative. Instead I found literature about growth and positive aspects resulting from chronic illness in journals of nursing or psychiatry. In my opinion, it is crucial that more anthropological research should be done in the filed of chronic illness, and should include the positive aspects people with a chronic illness can experience.

Challenges to drawing definite conclusions in the thesis include not only the complexity of the question I addressed, but also the limitations of my own research. For example, the short time of my fieldwork period made it difficult to directly address the illness experience, which was my topic. I tried to solve this problem indirectly, by relying on illness narratives to gain perspective on their experiences. Another problem I encountered during the process of writing was that I did not know how to analyze my interviews. During my anthropological education not much attention has been paid to deconstructing empirical data. I wondered to what extent I have to question what people told me and whether the empirical truth of what they said was indeed important for my thesis. As I think my research and anthropology in general is not about finding out the truth, but rather about reflecting, understanding, and explaining a situation, I did not mainly focus on whether people's narratives reflected their actual experiences. However, by means of triangulation and interpretation I tried to comer close to their experiences. Another difficulty which is related to the analysis of my data is that I did not know to what extent my presence and perspective should permeate the thesis. In my first year of my anthropological study I thought research should be about the group being studied and not about the anthropologist. Now, I think providing information about the researcher's own background adds insight, transparency, and value to the data.

As I believe that personal information can enrich a thesis, I will now provide a personal reflection based on my own experience. For years, I was unhappy with my situation. Although I had friends around me, I was unable to talk about my condition. For example, walking with a group of people, be it strangers, friends or family, I would tell them that I could only move slowly, yet still often found I was the last in the group. Feeling left behind in spite of my request was a hurtful experience, but I preferred to suffer instead of repeatedly asking whether the others could slow down. The only one with whom I shared my experiences was my diary. Reflecting in writing on my situation, I came to the realization that continuing like this would only make me unhappy. My reflection often was painful as it brought up hurtful memories. Yet, the pain was probably necessary to change. I can understand that some people might prefer to continue with their old lives and not allow thoughts or emotions which might change their situation. But I believe standing back and admitting that one is unhappy with the situation is the first step to transforming oneself in a positive way. Furthermore, one needs to have confidence that change is possible and that alternatives exist.

Thus, I slowly was able to open up and express my feelings. As a result people around me changed their behavior and became more considerate, which in turn made me feel better. I believe that changing yourself also impacts the behavior of the people around you. It is hard for others, especially non-disabled people, to know what a disabled person needs. Especially if an illness is not visible at first sight, people face challenges being considerate. It can be difficult to express what one needs, as one becomes vulnerable and risks that those needs will not be fulfilled. Yet, my advice would be to give expression a try. Thinking about some of my informants, I believe that if they could express how they felt, the people around them might change their behavior in a beneficial way. In the end, if people around them are not considerate and talking does not help the situation, then it is probably best to find new friends, maybe peers with a similar fate. For my own part, I find it important that others are considerate of me and accept me, but equally important that I accept myself. As I argued in my Bachelor's thesis, I believe that participation in reciprocal relationships can prevent exclusion. Due to an illness, it might be difficult to keep up one's reciprocal value. Yet, alternatives can also be found; if I cannot help my friends by carrying boxes when they move, I can make them coffee or offer mental support. Although living with a chronic illness at times can be hard, I think it is important not to be discouraged and not to give up. If an activity becomes impossible, an equally enjoyable alternative should be sought. Living with a chronic illness for so many years means, that for me, a part of the illness has become normality. Yet, as it progresses new challenges and problems never cease to appear. Finally, I hope this thesis has provided the outsider with some insight into the experience of a chronic and progressive illness. Although this is only a small contribution, I hope I created a bit more awareness about people with a disability.

6.2. Summary and Implications of my Research

In my thesis I explored how people experience Multiple Sclerosis and how differences in the experience can be explained. In the first chapter I demonstrated that there are three different forms of narrating the experience of Multiple Sclerosis. Half of the narratives of my informants describe normalization, in which people have accepted their conditions and try to live as normally as possible. Another fourth of the narratives centers on the experience of loss. This category is well-represented in the literature about chronic illness and disability. Narratives of people belonging to this category largely conform to society's general assumption about chronic and progressive illness. But there is also a category of narratives centering on posttraumatic growth, which call attention to the fact that general assumptions are of little use when the experiences of chronic illness vary widely among individuals. Moreover, a negative bias towards the chronic illness experience has to be avoided. Another major finding is that the experience of the body reflects how people experience their illness. Yet, as one might assume, the severity of the symptoms is not directly related to the illness experience.

In the second chapter I analyzed different factors in order to explain why people experience their illness so differently. I used factors which are discussed in theories about resilience and added some that are specific to chronic illness. The result of this analysis is that it is impossible to determine one or two single factors which explain the differences in the illness experience. All factors to a certain extent shape the experience, but their composition differs for each individual. It seems doubtful whether determining risk and protective factors for people with a chronic illness is at all fruitful. Indeed, I argue that individual differences are too large to admit the possibility of a combination of factors which could universally explain those differences.

However, one aspect that all illness narratives share is that they describe a transformation. Multiple Sclerosis transforms the lives of all affected by it. But while some experienced a positive transformation, others experience a negative one. In the third chapter, I analyze this transformation by applying the concept of rite of passage and liminality. I illustrate the argument that all people who have been diagnosed with Multiple Sclerosis go through a period of liminality. An important point is that liminality provides room for reflection and change. Isolation and ambiguity apparently enhance transformation. Whereas some reside in that phase, others are able to leave it. People who are stuck in a liminal phase experience more problems with their illness than people who have left this phase. I argue that people are able to transcend liminality by striving for normalization, entering into a disability culture, or by transforming the illness experience into personal growth. Hence theories that state that people with a disability are forced to live at the margin of society are outdated. Nowadays, society's treatment of people with a disability has changed in many ways, and they can live with a valid status among 'normal' people.

The concept of liminality helps to clarify the importance of some of the factors discussed in a previous chapter. Liminality is a state of ambiguity; thus, in transcending it, it does not matter so much whether people have social support, work, or other factors. Rather it is important that they have found a clear position, both in regards to themselves and others. For example, it is not so important that they experience strong support in their old or new social network, but rather that they, their friends, and their family clearly and unambiguously accept the condition. This makes it easier to deal with the illness. Likewise, it is not necessarily important whether people are able to work or not, but rather that they feel worthy without work. As to lifestyle changes, one can argue that it is not the extent of the changes that plays a role but whether people have adapted their live successfully to their new situation and gained a new valid status in society. Thus, what counts is whether people are able to change their attitude towards their situation and their environment.

An implication of my research for health care workers or other people who are in contact with people who have a chronic and disabling illness is that it is important not to assume that illness must be an entirely negative experience. By realizing that it can be a positive experience for some, such caregivers may even be able to aid people in transforming their illness experience into something positive. Another important aspect, which could be used in therapy, is to provide people with room for reflection. Observing one's situation from a distance can sometimes open up new possibilities. Along these lines, developing and using rites of passage might help people deal better with their situation. Such rituals might center on receiving social support and being inspired to trust in one’s own capabilities. Another discovery of my research is that anthropological concepts with which to analyze the variety of illness experiences are lacking. The question of why some people are able to bounce back after a traumatic event is addressed within psychology, but rarely within anthropology.

The overall message of my research is not to assume that chronic illness and disability are negative phenomena. First, people can experience their illness in a positive way; not everybody is overwhelmed by the problems resulting from the condition. Second, the situation of people with a disability in our society has changed, and not all people with a disability are excluded from society. 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.

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8. Epilogue

Conduction this research was a personal journey for me. A few years ago I could not imagine studying people with a similar condition. I did not really want to be confronted with my own situation. Since before this study I did not really have contact with people suffering from a similar condition, doing this fieldwork I was able to meet people with a similar fate and to explore how they live with their illness. I saw people who physically are worse off than me and was confronted with my possible future, but I also visited people who are better off than me. Seeing people who are older than me but have milder symptoms was strange initially; and remains so to a certain extent. At some points I doubted whether in the future I would like to continue with the topic of chronic illness, because the topic sometimes hit very close to home. Having a similar background to my informants, I not only understood what they were talking about, but I felt it, which at times can be painful. Seeing people who have just been diagnosed, who struggle using a walking aid, who feel that they cannot do what they want to do anymore, who are pretending to the outside world that they are fine, who feel threatened by the progression of their illness, who do not want to accept the help of others, who feel isolated in their situation – all this reminded me of my own past and present situation. Yet, in spite of the difficulty of this topic, I believe that it is important to give voice to people with a chronic and disabling disease. That means calling attention, both to people who are struggling, and to people who master their illness most of the time. While some stories of loss might have been discouraging, other stories have been very encouraging. Some people displayed great strength and willpower and grew through their situation. What I personally learned from this research is that the quality of your life does not necessarily depend on your symptoms, but on the way how you deal with the situation. I think accepting your situation without giving up, being accepted by your friends, family and society, being able to improvise and a good dose of humor all help in living with a chronic condition.

Finally, the process of researching and writing my thesis was a sort of *rite de passage* for me. First I prepared myself to leave my known social world and enter into a partly unknown world of chronic illness and disability. Having developed an idea into a research proposal, I was ready to leave. Stepping out of the airplane in Dublin I entered the liminal phase. In different ways I had an ambiguous status. I was studying anthropology but was not an anthropologist yet. I was an insider as I shared a similar fate with my informants, but at the same time an outsider studying them. As in the beginning I did not know many people yet and spend a lot of time transcribing my interviews, I was isolated from society. However, I used that isolation for reflection and as a consequence changed my research question. Returning to Amsterdam, my liminality and isolation continued as I was sitting behind my desk while my friends were on holidays. This time in Amsterdam was characterized by feelings of uncertainty and disorientation. I wrote and wrote, questioned what I wrote, scraped what I wrote, pondered, and rewrote. Now, I hope that the completion of my thesis will allow me to return to society with a new academic status.

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10. English Summary

This thesis is based on a four-month fieldwork period in Dublin, in which I studied twenty people who had been diagnosed with Multiple Sclerosis, a chronic and progressive disease of the central nervous system. Its main symptoms are fatigue, muscle weakness, balance and coordination problems, pain, stiffness, difficulties with speech, incontinence, and neuropsychological problems. In the literature about chronic illness a relatively negative attitude towards chronic illness exists. With my research I want to provide insight into what it is like to live with a chronic illness and how differently people experience their illness. Moreover I want to explain why some people struggle with their illness, while others are able to deal with it well. My research question therefore is: how do people with Multiple Sclerosis experience their illness and how can differences in their experience be explained?

In order to answer that question in the first main chapter I discuss different experiences of Multiple Sclerosis. Analyzing my data obtained from interviews and observations, three different forms of narrating the experience of Multiple Sclerosis emerged. I rely on illness narratives to gain perspective on people's experience. The first category of illness narratives describes normalization. People whose narratives fall into this category have accepted their illness as playing a part in their lives, but not a dominant one. This category is subdivided into narratives that describe normalization, on the one hand with regards to people's old reference group and on the other hand with regards to a new reference group, which mostly consists of people suffering from the same or a similar condition. The second category comprises narratives in which the experience of losses is central. People whose narratives fall into this category emphasize their losses, worries about the future, and difficulties with the present. The third category of illness narratives consists of people who experience posttraumatic growth, a concept deriving from psychology describing the experience of positive change after a traumatic event. People whose narratives belong to this category have a greater appreciation for life and have made new priorities. In general they are quite able to deal with their condition well. Contrary to the literature about chronic illness I show that there is a variety in the illness experiences.

In the second main chapter I analyze different factors in order to explain why people experience their illness so differently. My central question is why some people experience their illness as a negative interruption of their lives, while others have given it a positive meaning. I first analyze to what extent lifestyle changes in the social network, employment, and leisure time impact on the way people experience their illness. Thereafter I review individual factors, such as, the time

of the diagnosis and age, gender, functional disability, dependence, and visibility. Finally I debate the role of spirituality in the illness experience. This chapter ends with a discussion of the extent to which these factors help explain differences in the illness experience.

My conclusion of that chapter is that an analysis of different factors is not very fruitful, as the factors seem to vary for each individual. Therefore, in the third main chapter, I present a different framework to study the illness experience. Analyzing the illness narratives, I was struck that all informants describe a transformation process, whether positive or negative. In anthropology the concept of rite of passage is used to analyze transformations. By applying the concept of rite of passage and liminality, I deconstruct the different illness experiences. I illustrate that people who remain in a liminal phase and who are torn between two worlds, experience more problems than people who are able to leave this phase. Using empirical examples I demonstrate different paths to exiting liminality, namely by entering into a disability culture, striving for normalization, or by creating growth from one’s experience. I address why some people are able to leave the liminal phase, and while others still reside in it. Discussing the importance of rituals and ceremonies I want to show how people can be helped to deal with their condition.

I end my thesis with a personal reflection and the implications of this study. An important conclusion of my research is that the experience of a chronic and disabling illness varies greatly for each individual. In this thesis I critique the negative bias prevalent in studies about the experience of chronic illness, and assert that the majority of my informants are able to deal well with their situation, while some even experience personal growth. Instead of analyzing various factors in order to explain differences in the experiences, I apply the concept of rite of passage which can better illustrate why people experience their illness so differently. I argue that reflection is a crucial aspect of liminality which stimulates people to transform their illness experience in a positive way. Rites of passage or ceremonies, which are especially developed for people with a disability, could help individuals in providing space for reflection and transformation. Finally, my thesis gives voice to people with a chronic and disabling illness and provides insight into their illness experience.

11. Dutch Summary/ Nederlandse samenvatting

Deze scriptie is gebaseerd op veldwerk in Dublin, waar ik gedurende vier maanden onderzoek heb gedaan naar mensen met Multiple Sclerose, een aandoening van het centrale zenuwstelsel die verschillende symptomen kan hebben zoals spierzwakte, coördinatie en balansproblemen, pijn, stijfheid, problemen met taal, incontinentie en veranderde waarneming en zelfbeeld. In de literatuur over chronische ziekte is een relatief negatieve houding met betrekking tot chronische ziekte vast te stellen. Mijn onderzoek zal bijdragen aan een beter begrip voor het leven met een chronische ziekte en zal laten zien op welke verschillende manieren mensen hun ziekte beleven. Bovendien wil ik proberen te verklaren waarom sommige mensen problemen met hun ziekte ondervinden terwijl anderen er redelijk goed mee om kunnen gaan. Mijn onderzoeksvraag is daarom: hoe beleven mensen die met Multiple Sclerose gediagnosticeerd zijn hun ziekte en hoe zijn verschillen in hun ziektebelevenis te verklaren?

Om de vraag te beantwoorden presenteer ik in het eerste hoofdstuk van mijn scriptie verschillende vormen waarop de ziekte wordt ervaren. Uit mijn empirische data kwamen drie verschillende vormen van ziekteverhalen naar voren. Ik gebruik deze verhalen om zo dicht mogelijk bij de ziekte ervaring van mijn informanten te komen. De eerste categorie beschrijft normalisering. Mensen met deze ziekteverhalen hebben geaccepteerd dat hun ziekte een deel van hun leven uitmaakt, maar toch proberen ze zo normaal mogelijk te leven. Deze categorie is onderverdeelt in normalisering met betrekking tot enerzijds de oude referentie groep en anderzijds een nieuwe referentie groep. Mensen met verhalen die horen bij de eerst subgroep proberen zich in de ‘normale’ maatschappij te integreren. Binnen de tweede subcategorie vergelijken mensen hun situatie niet met die van gezonde mensen, maar met die van mensen met een soortgelijke aandoening. De tweede categorie bevat verhalen van mensen die vooral verlies, zorgen over de toekomst en moeilijkheden met het dagelijks leven benadrukken. De derde categorie behelst verhalen van mensen die posttraumatische groei ervaren. Dit is een psychologisch concept dat positieve veranderingen na een traumatisch gebeurtenis beschrijft. Mensen die posttraumatische groei ervaren kunnen redelijk goed met hun aandoening omgaan, waarderen hun leven meer dan voordat ze ziek werden en hebben nieuwe prioriteiten in hun leven gevormd. In tegenstelling tot de literatuur over de belevenis van chronische ziekte laat ik zien dat er een grote variatie is in hoe mensen hun ziekte ervaren.

In het tweede hoofdstuk analyseer ik uiteenlopende factoren om te verklaren waarom mensen hun ziekte zo verschillend ervaren. Mijn centrale vraag is hier waarom sommige mensen hun ziekte als negatieve gebeurtenis beschouwen, terwijl anderen de ziekte een positieve betekenis geven. Ik analyseer eerst tot welke mate veranderingen in levensstijl, zoals in het sociaal netwerk, werk en vrijetijdsbesteding de ziektebelevenis beïnvloeden. Daarna bespreek ik de invloed van individuele factoren zoals tijdstip van de diagnose, leeftijd, gender, de mate van functiebeperking en de zichtbaarheid van de aandoening. Vervolgens ga ik in op de impact die spiritualiteit op de ziektebelevenis kan hebben. Ten slotte discussieer ik tot welke mate deze factoren kunnen helpen om verschillen in de ziektebelevenissen te verklaren.

Mijn conclusie van het tweede hoofdstuk is dat een analyse van bovenstaande factoren niet erg nuttig is omdat de samenstelling en het belang van de factoren voor elk individu verschillen. In het derde hoofdstuk gebruik ik daarom een ander kader om de ziektebelevenissen te bestuderen. Omdat alle informanten een transformatie beschrijven gebruik ik de concepten van *rite de passage* en liminaliteit om de verschillende belevenissen te analyseren. Ik betoog dat mensen die in een liminele fase verblijven meer problemen met hun ziekte ondervinden dan mensen die de liminele fase hebben verlaten. Zoals ik laat zien, zijn er verschillende wijzen waarop mensen de liminele fase kunnen verlaten, namelijk door het betreden van een gehandicapten cultuur, door normaliseren en door het creëren van groei. In het volgende gedeelte bediscussieer ik waarom het sommige mensen lukt de liminele fase te verlaten en waarom anderen nog steeds daarin verblijven. Ik beëindig het hoofdstuk met een discussie rond het belang van rituelen en ceremoniën die mensen kunnen helpen beter met hun ziekte om te gaan.

Afsluitend geef ik een persoonlijke reflectie op het thema en bespreek de implicaties van mijn onderzoek. Een belangrijke conclusie is dat mensen hun ziekte heel verschillend beleven en ervaren. Deze scriptie bekritiseert een negatieve bias en maakt duidelijk dat het belangrijk is om niet aan te nemen dat een chronische ziekte een uitsluitend negatieve ervaring hoeft te zijn. Het merendeel van mijn informanten kon goed met hun aandoening omgaan en sommigen beleefden zelfs persoonlijke groei. In plaats van verschillende factoren te analyseren om onderscheiden in de ziektebelevenis te verklaren, pas ik het concept van *rite de passage* toe. Dit verduidelijkt beter waarom mensen hun ziekte verschillend ervaren. Ik betoog dat reflectie een belangrijk aspect is die mensen kan helpen om beter met hun ziekte om te gaan. *Rites de passage* of bepaalde ceremoniën die voor mensen met een handicap zijn ontworpen, kunnen ruimte voor reflectie creëren en mensen helpen te transformeren. Ten slotte wil ik met mijn scriptie aandacht vragen voor mensen met een chronische en progressieve aandoening en inkijk bieden in hoe mensen hun ziekte ervaren.