

Visibility and invisibility in chronic illness

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Does the visibility of a condition necessarily lead to stigmatization? Is it easier to suffer from an invisible than a visible condition? And what are the consequences of living with an invisible or visible illness? In this article the author draws on the concepts of stigma and concealability to argue that the visibility of a condition does not necessarily lead to stigmatization, but that people can use visibility strategically. This article further demonstrates that even if people disclose their illness it can remain invisible to people whom they encounter. The author uses empirical examples from qualitative research in Dublin among twenty people who have been diagnosed with Multiple Sclerosis. In addition, she draws on her own experience of living with a chronic condition.

[visibility, invisibility, chronic illness, disability, body, Multiple Sclerosis]

It was late at night in Arnhem. My friend and I wanted to take the last bus to her place. In order not to miss it we went there several minutes before the last bus should arrive. When the bus finally came, my friend got in, but I could not get in because the bus stopped too far away from the pavement. I explained to the bus driver that because of my muscle illness I could not get into the bus like that and asked politely whether he could either lower the step or drive closer to the pavement. He did neither and just drove away. A few years later in a national park in Argentina I was motioned aside and was able to skip the queue. In addition, I did not have to pay the entrance fee. In this article I do not want to discuss how disability is treated differently in different countries, but I want to analyse something else that made people react differently towards me: visibility. In Arnhem I just appeared like a normal young woman whilst in Argentina I travelled in a wheelchair.

Scholars often assume that disclosing a condition leads to stigmatization as people no longer can pass as 'normal' and are therefore treated differently. Although it is acknowledged that there is a spectrum between concealment and disclosure, not much has been written about how people can actively shape their visibility or invisibility. Instead of focussing on why people choose to hide or disclose a condition, as most authors do, in this article I shall concentrate on the consequences of living with an invisible or visible condition and the active role people can play in how others perceive

them. First I argue that the visibility of a chronic condition does not necessarily lead to stigmatization, but that people can shape strategically how they are perceived. Second I demonstrate that even if people disclose their illness, it can remain invisible to people they encounter. I draw on empirical examples from my anthropological fieldwork in Dublin, where I interviewed around twenty people with Multiple Sclerosis. Most of my informants were introduced to me via the Irish MS society, a few via snowball sampling. Their age ranged from twenty-four to seventy-six years, half of them were men, and half women. My informants belong to various social classes, ranging from upper to working class. They have different forms of Multiple Sclerosis and different grades of disability. I applied qualitative research methods and interviewed half of my informants more than once. In addition to the data, which I gathered during my fieldwork I reflect on my own experience of living with a chronic condition.¹

Visibility and stigma

When discussing visibility one cannot avoid Goffman's analysis of stigma. Etymologically the word 'stigma' derives from the Greek. 'Stigma' was used to mark people who were seen as different. Signs that were cut or burnt into the body of the flawed made them visible to society and made it possible for society to avoid those people (Goffman 1963: 1). Nowadays deviant people are not marked in this way, but often they are still shunned by society. In order to explain stigma it is important to realize that whilst everybody has a social identity, that how someone is perceived does not necessarily conform to their actual social identity. Goffman calls those two categories 'virtual social identity' and 'actual social identity'. The first category describes how people perceive somebody at first impression and the latter depicts the qualities a person really possesses. Stigmatization then describes a process in which certain individuals or groups of people are reduced to a number of characteristics.

As virtual and actual social identity often differ, stigma explicitly describes an attribute that is deeply discrediting.

He [the stigmatized] thus is reduced in our minds from a whole and usual person to a tainted, discounted one. Such an attribute is a stigma, especially when its discrediting effect is very extensive; sometimes it is also called a failing, a shortcoming, a handicap. It constitutes a special discrepancy between virtual and actual social identity (ibid.: 3).

In other words, Goffman depicts a stigma as an "undesired differentness" (ibid.: 5). He argues that it is important whether the condition, which qualifies a person as 'not normal', is known or unknown to other people. In the first case the person is discredited and in the second discreditable. This distinction determines how people are treated and which strategies they can use. If somebody manages to hide his or her condition on the one hand he or she is able to avoid stigma, but on the other hand the person has to live with the constant risks that the condition will be disclosed. Goffman describes two different strategies for concealing a condition. The first, which he calls 'covering'

describes an attempt to minimize the stigmatizing effects of the condition. Thus, when other people can see the condition, the stigmatized person tries to minimize the obtrusiveness of the stigma. The second is 'passing' and refers to the active concealment of the condition in order to pass as normal and to belong to the 'normal' group (Goffman 1963). Yet, there are also people who possess an invisible stigma: "a condition that is not perceptible, not noticeable, not evident to others. In short – a condition unseen to others" (Vickers 1997: 241). Goffman (1963) points out that those people might have to deal with 'unsensitised' others, who do not understand or see the stigmatizing condition.

Jones et al. (1984) further developed Goffman's theory. They generated six dimensions that shape the stigmatized person's experiences. The first dimension, concealability, describes the degree to which the condition can be concealed and how visibility can be controlled. The second dimension, course of the mark, describes the progression of the illness. Disruptiveness, the third, depicts extent to which the illness shapes social relations. A person who stutters can for example experience difficulties in conversations with others. Aesthetics, the fourth dimension, deals with the 'ugliness' of a condition. Society might for example avoid people who have a burnt face. Origin, the fifth dimension, is important because if somebody is born with something, he might be treated differently than when society believes he is responsible for his condition. The last dimension describes the danger, like contagion, attaching to a condition. The first dimension is of interest for this article. As the degree of visibility has important consequences for how the person is treated, Jones et al. observe that many people try to hide their condition (1984: 29). Yet, even if the condition can be concealed and is not visible to others it can shape social relationships. First of all, people might not be able to accomplish the tasks they could accomplish before they became sick. They might not be able to work full-time or help in the household and they might have to cancel appointments, for which cannot muster the energy. In addition, hiding one's condition can create feelings of shame and guilt. People might feel bad about the fact that they hide something and have to lie to people. Moreover, they have to live with the fear that their condition might be discovered.

Joachim and Acorn (2000) develop a framework to describe the relationship between stigma and the decision to hide or disclose a chronic illness depending on its visibility or invisibility (2000: 243). First they divide conditions into visible and invisible conditions. They argue that people have limited choices when the illness is visible. When it is not, people have the choice to cover it. Yet this is only possible to a certain extent. Instead of disclosing one's illness people also have the choice to inform others about it. Informing implies that people can control how, what, when and whom to inform. Moreover the informer takes an objective position and does not seem to be concerned about people's reactions with regards to the condition (Charmaz 1991). Joachim and Acorn (2000) assume that when the condition is revealed people encounter stigmatization and are discredited. The only option they have is how to deal with stigmatization and to what degree they let it affect them. When the condition is invisible people have three different options; they can choose between disclosure, non-disclosure or preventive disclosure. The first path may, depending on different

factors, lead to either stigmatization or support. The second path makes it possible for people to pass as normal, but it also contains the danger that they are caught in a lie. The third path means that people disclose certain aspects of the condition in order to counteract stigma. Thereby they can prevent or correct negative prejudices. It is striking that the majority of paths leads to stress and problems. Joachim and Acorn's framework also ignores the fact that there is a continuum between complete secrecy and complete information (Goffman 1963: 94-95). Furthermore visibility and invisibility are separated, but in practice an illness can have visible and invisible symptoms.

Grytten and Måseide approach stigmatization and chronic illness in a different manner. They analyse how people with Multiple Sclerosis use information management to counteract stigmatization in social interactions (Grytten & Måseide 2005: 232). They argue that people who suffer from a chronic illness can manipulate their identity and act differently in various social situations (*ibid.*: 233). The authors agree with Mol (2002) who introduces the "body multiple" as a complex reality in which patients, relatives and health professionals live and act out their diverse version of the disease, and in which diseases such as MS have many meanings" (*ibid.*). Similarly, Taylor 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). Thus, bodies can be enacted differently in various settings. In a hospital or with a public health officer people might emphasize their bodily weaknesses and problems whereas when they are with their friends they might want to present themselves as strong and capable. Grytten and Måseide state: "The body is the medium for others' perception of us, our inner qualities; the intentions, meaning, character and personality" (2005: 232). Hence, people perceive someone through his body. When communicating about Multiple Sclerosis the body plays a central role.

In conclusion one can say that the majority of authors have a rather negative perspective on the disclosure or non-disclosure of a chronic condition. Either way people encounter problems. Furthermore most scholars present and approach people with a chronic illness as being rather passive. Grytten and Måseide (2005) in contrast acknowledge that there are different strategies people with a chronic condition can use in order to counteract stigmatization. In this article I follow Grytten and Måseide in approaching people with Multiple Sclerosis as agents who can enact their illness differently in various settings and who can shape the visibility and invisibility of their condition. I show that there are more categories than simply 'visible' or 'invisible'. I demonstrate that visibility and disclosure of an illness does not necessarily lead to stigmatization, as in certain situations people are able to shape strategically how they are perceived and treated. Moreover, I argue that disclosure of an invisible illness does not necessarily mean that outsiders see and understand the illness. When people do not see anything that is wrong, although they know differently, they still might treat the person as if he or she were healthy. As chronic illness happens in the body and often only is visible when the person is moving, in my analysis I touch upon the body as moving subject.

Before going on to discuss visibility and invisibility in chronic illness, let me first say something about Multiple Sclerosis. Multiple Sclerosis is a disease of the nervous system, which leads to the loss of bodily functions. The main symptoms are numb-

ness, 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). As Multiple Sclerosis is a progressive illness people who have been diagnosed with it constantly have to adapt to their body. Loss of function for them is an on-going process. With regards to visibility Multiple Sclerosis is especially interesting because with further progression the illness becomes more visible. In addition, the illness can have both visible elements (like a limping leg) and invisible elements (like fatigue or pain).

The visibility and invisibility of an illness is connected to a broad scale of techniques like using devices in order to walk, moving in a different way or lacking the energy to move adequately. Multiple Sclerosis is most visible when people have to use a walking aid, like a stick, a walking frame or a wheelchair. Yet, that does not mean that all aspects of the illness are visible. Fatigue, pain or stiffness are symptoms which cannot be seen. Furthermore, Multiple Sclerosis is a progressive illness, which means that the illness in the beginning is mostly invisible whereas with further progression it becomes more and more visible. When talking about disclosure it is important to realize that people might disclose their illness to their family and friends, but perhaps not reveal it to their employer or to acquaintances.

Visible illness

When an illness is visible people can encounter a number of problems. Several scholars point out that people might have the feeling that their illness is taking over their identity (Goffman 1963; Kurzban & Leary 2001). “One of the most fundamental of these [problems] is that disability so often overshadows personal identity” (Susman 1994: 19). Connor, who is in his late fifties, has the feeling that he is the “fellow in the wheelchair” rather than the person he used to be. Peter, who is in his early fifties, also experienced this when using a wheelchair.²

People do perceive you differently in a wheelchair. There is quite a large store over here. It is quite big and I couldn't walk around anymore. I have a good friend and he brought me over there. We decided to use the wheelchair and I was amazed at the attitude of people. I felt like I wasn't a normal human anymore. I was made to feel like somebody different. Okay, that was maybe for an hour and the fact that I was in a wheelchair for that time, it had such an effect on me. That did affect me like I said, I became quite depressive for a few days, I can't say I can do that every time.

His experience of being in a wheelchair was rather negative. He also reports that people addressed his friend with questions instead of talking directly to him. One

explanation for this might be that people tend to generalize from a particular disability to a variety of disabilities (Strauss & Glaser 1975). In Peter's case, people might think that he is not only physically disabled, but also has mental or developmental problems. But even if people do not generalize to other disabilities, according to many of my informants they behave differently towards them. For example, they still stare at the person in the wheelchair. In order to avoid people's gazes Connor decided to put on dark sunglasses when he is in the wheelchair.

If before I had seen somebody in a wheelchair, I probably looked away immediately, thank God, I am not in the wheelchair. That's why I wear dark glasses, even in the middle of winter, so that I don't have to make eye contact with people. People look unintentionally. So I wear dark glasses so I am not making eye contact with people. There is a difference. People do look differently, you know.

Thus although people do not say anything their body language can convey the message that they look down at the person in the wheelchair or that they consider the person to be pitiful.

However, even as people might not have experienced that people ignore them, they still might feel that society perceives them differently. Emily, who in her opinion deals very well with her condition and is very open about it, still feels that the disability takes over her identity.

I used to be lovely. I am tall, when I could walk, so I used to be...with a disability you are less of a woman. I do think that you are less of a woman.

This quote shows that disability can also shape the perception of a person's gender. Many people with a chronic illness experience what Goffman (1963) calls 'awkward encounters' between stigmatised and 'normal' people. Connor expresses that people do not know how to treat him, because for example helping somebody out of the wheelchair is a new and awkward situation for them.

Then there is the whole awkwardness of getting in and out of things. Then you are less inclined to do them, because you immediately see all the difficulties. It's not worthwhile.

Thus, Connor tends to stay at home in order to avoid such situations. As this isolates him, one can conclude that for him it is difficult to deal with people's gazes and behaviour, otherwise he would probably not choose to remain in his house.

But an illness like Multiple Sclerosis can also be visible in a different way.

There is one man in the MS centre, but he could not comb his hair, so just that one thing. His hair was all over the place, so it gave him a sort of mad looking appearance, you know what I mean, you wouldn't talk to him. When he got his hair cut, he looked totally different, but because he had his hair all over the place, you'd say mhm...and that's just a small thing with a knock on effect.

In the case of this man the illness is not made visible by use of a walking aid or a wheelchair, but the illness makes it impossible for him to comb his hair. Thus Connor tells me his hair influences strongly how he perceived this man. Hence, when discussing visibility one should not overlook that the illness can be made visible in various ways. If people do not get care at home for example, looking after themselves or their house can demand a large be a large effort from them. Although people would prefer to look different or have a clean house, they might spend their energy on things that have a higher priority for them.

So far I have only talked about people whose illness provokes stigma and who have had rather negative experiences with their disability. Different scholars note that people who do not have the possibility to conceal their illness will encounter also stigmatization. But does this necessarily apply to everyone? During my research I also met some people who did not report those problems.³ Caitlin who is in her late fifties says she has never found that people talk to her husband instead of addressing her directly.

No, I don't think so, I don't feel excluded like that. I am a chatty type of person and I wouldn't be slow to come out, with chat and that. I never felt that really.

A possible explanation might be that she is, as she calls it, a chatty person who has no problems talking to people. Another person who reports not to experience any problems when meeting other people is Anna.

My experiences on the whole have been quite positive. What I would hate if people would instantly label you and would not try to get to know you, because I am quite more that my working stick.

Although her experiences have been generally positive, she is aware of the fact that people might first look at her disability and not at her as a person. Anna admits that with her friends, family and colleagues this is not a problem, but when meeting new people she sometimes feels that people only see her disability. She believes, however, that people's reactions depend to a great deal on how the person concerned approaches his or her own disability.

Concluding, one can say that a majority of people experienced that society perceives them as different. Some also report that they feel overshadowed by their disability. Yet, not everybody has had this negative experience, and by behaving in an agentive way people seem able to shape the way people react to them.

Invisible illness

But what are the consequences of having an illness of which the symptoms are not always visible? During my research I talked to some people who did not have symptoms that influenced their mobility, but who suffered mainly from fatigue. On the one

hand they are happy that their illness is not directly visible. The fact that the illness is not directly visible does not however mean that people from their social network do not know they have it. The majority of interviewees report that people who are close to them know of their condition. Yet, as in their cases the illness is not directly visible this knowledge often fades into the background and people are not aware of it all the time. As a consequence “few will be understood by relatives, friends or colleagues, simply because the symptoms cannot be seen” (Vickers 1997: 241). When because of his or her fatigue somebody has to cancel an appointment, the other person might not tolerate or accept this behaviour, as he cannot imagine that tiredness can have such an impact on a person. Suffering from nonvisible symptoms can signify that people cannot accomplish everything that they want to do, but that it is harder for them to have this fact acknowledged. Like in the case of Séan, twenty-four years old, who feels that other people perceive him as being lazy.

People think I am lazy all the time. It's not my fault. I hate when people say, you don't look sick. It's just the worst thing you can say.

The fact that he does not look sick is not necessarily an advantage as he is sick, but does not receive much acknowledgement. He is not the only one who tells me that people often state that they are tired as well, but still do the things that are important to them. For most people this is very difficult, as they feel misunderstood and not accepted. When people have certain symptoms, but have not yet received a diagnosis, it can be even more difficult for them. They themselves are not sure what is happening to them and whether they are maybe just imagining their symptoms. Other people, on the other hand, will tell them not to make a fuss and just continue doing what they used to do. Although receiving a diagnosis of a chronic and disabling disease comes as a shock to most people, many are relieved finally to have an explanation for their symptoms (Robinson 1988: 31).

Apart from not receiving recognition when the illness is not directly visible, people might feel that they are treated differently.

It's realizing, I am still me. I am a different person, but I am still me. That's how I look at it. Okay, I have MS, but so what...I am still me. Let me be me, right. Don't look at me as MS, look at me as Alex. He has MS. Look at he for who I am. So I have MS, right, it restricts me in some things, but I am still me. Ask me. Is Alex alright? I think that is the biggest insult.

Even though Alex' illness is not directly visible his friends treat him differently. This probably is a result of people's ignorance. Even if they know what Multiple Sclerosis is, they might not know how to deal with a person who has it. Thus in this case disclosure of the illness, although it is not directly visible, leads to stigmatization in the sense that people perceive him differently.

When the illness is not visible people might also experience that people imply that they do not deserve certain privileges like a free parking space (Vickers 1997: 244).

I feel sometimes when I use the disabled car sticker, when I get out of the car...people think, she is not disabled, what is she using the car sticker for. I want to go, actually I deserve this, I need this. That can be a bit funny. You find people thinking, if she is not in a wheelchair, she is not disabled. You know, I wouldn't try to park in disabled car space if I don't have to, but I almost fell...

In one case I talked to a person who mostly hid his condition. But he expresses fear that people might find out about his condition and then treat him differently.

Year, people react differently, that's what I am afraid of. You don't want to put people on the spot, they don't know how to react, they don't know... The leg they can see but the rest not...it's a disease, a hidden disease.

He thus struggles with what several authors describe as the fear that his illness will be disclosed. Although he does not want people to know that he is sick he also thinks that if people knew he has Multiple Sclerosis, they would only know certain parts. In his opinion Multiple Sclerosis can be compared to an iceberg where only a small part is visible but the rest remains hidden. In other words, Multiple Sclerosis consists of visible and invisible elements, some of which can be disclosed to others. But it is probable that many elements of the illness remain unknown or inapprehensible to the outsider.

With regards to the invisibility of an illness or of certain symptoms it is important to realize that this not only has advantages. People do not only have to deal with the fear that their condition might be discovered, but they also struggle for acknowledgement. People whose illness is not visible can pass as normal if they want to, but the empirical examples show that this is not always felt to be desirable. The majority of people I interviewed told their family, friends and even colleagues that they have MS.⁴ Yet this does not mean that those people always understand and are considerate of it. In addition people whose illness is not immediately visible experience problems in encounters with strangers.

Illness that can be made visible or invisible

In the previous sections I have written about visibility and invisibility of Multiple Sclerosis. In this one I want to call attention to the fact that illness in a certain state can be made visible or invisible: something often overlooked by scholars. Thus in the following I focus on this in-between category where people strategically manoeuvre between those two categories. As Multiple Sclerosis is an illness, in which symptoms can differ from day to day, in certain situations people have the possibility to make their illness visible or invisible. It is important to note that when talking about visibility and invisibility one has to take the context into account. People do not merely make their illness visible or invisible, but they do so in different context. They decide in each case to whom, how, when and where they hide or disclose their illness (Goffman 1963: 57; Charmaz 1991).

An example of how a person can actively influence his visibility is Alex, who tells me that when he parks at a disabled car park, for which he has a sticker, he limps more when he gets out of the car. In order to prove to people that he deserves the car park, he makes himself more disabled than he actually is. He thus uses his body in an agentive manner and by emphasizing his disability he tries to receive recognition. Yet on the other hand structure forces him to behave like that. Asking for any service from a government institution is another situation where somebody might make himself more disabled than he actually is. If somebody comes to my place to judge whether I need any adaptations in my house I might also get up a little more awkwardly than I normally do.

Using a walking stick although one does not necessarily need one is another example of actively shaping visibility. I talked to several people who said that they used a walking stick because then people would be more considerate and be careful not to accidentally bump into them. The main function of the stick in that case is that it works as a signal. However, from my own experience I can say that I was reluctant to use a stick for that purpose, because it also makes you look more disabled. I believe when talking about visibility people can actively ponder which behaviour has more advantages than disadvantages. This consideration is very individual and differs from person to person.

How people weigh the advantages and disadvantages can also change over the years. I remember that in my teenage years I was very anxious about disclosing the illness. Here it is important to make a distinction between disclosing and informing. Informing only means to tell people about one's diagnosis and not necessarily about the physical and emotional consequences it has for one's life (Charmaz 1991). Thus although I informed quite some people about my illness, I tried not to let it be visible. Hence informing people about your condition does not necessarily mean demonstrating to others that you are sick. Even though you inform people about your condition you might pretend that physically and emotionally it hardly affects you. In practice this meant that I got up when nobody was watching and I did not show people when I was tired. My main motivation in doing so was probably not to come across as weak or as different from the rest. But this also meant that I would have to pay a price. Not telling other people that I was too tired to do something meant that the next day I would be completely exhausted. After some years of reflection I realized that this is probably not the best way to deal with my illness. I also experienced that if I do not emphasize that I am sick and do not function like a healthy person, I will not receive help from strangers. Often people were not willing to let me go by elevator and told me that as I have two legs I could take the stairs. Or, as I wrote in the beginning, quite some buses passed without me being able to get in as bus drivers did not perceive me as needing help. I believe that being clearer about your situation and your restrictions makes it easier for the social environment to act in an appropriate way.

During my research several people told me that if you do not feel awkward about your situation, it is easier for other people to deal with you. In general I observed that people who experience many problems with their illness also describe encounters with strangers as awkward and problematic. In contrast, people who have accepted

their situation and are able to be clear about it, experience less difficulties. Hence, I argue that in certain situations people can strategically shape how society perceives and people treat them. Grytten and Måside demonstrate this in a discussion about whether people prefer to let others believe they are either sick or drunk.⁵ They argue that being labelled as drunk in one context might be more morally degrading than having MS, but in another context the contrary might be the case. Thus when people want to enter into a club they would rather disclose that they have MS than to appear drunken. Yet at work, where drinking is not tolerated anyway, a man prefers to make a joke about drinking in order to conceal his illness and distract from it (Grytten & Måside 2005: 239).

Thus, although I agree that disability is also created by burdens in society and not only the result of functional limitations, I am of the opinion that people's agency can shape how people perceive their disability. An example illustrates my point. For years, when walking with a group, I was normally the last person, walking a few meters behind the rest, even though I told the group that I cannot walk so fast and had asked them to walk slower. Yet, after a few minutes the group got back to their old tempo and I fell behind. When I was with friends, sometimes I was lucky that somebody would walk with me ten or a hundred meters behind the group. But walking with strangers or people I hardly knew made it even more difficult to joint the group. So instead of enjoying a sightseeing tour or a hike through nature, I was just focused on my feet, trying to catch up with the rest and not to fall. The whole experience was quite painful, especially when with friends. After some years of frustration I finally decided to stand up for myself a bit more and to mention that it is quite painful to always be the last and always to hurry behind the group. Expression of the pain and frustration, and more often reminding people to walk slower, finally helped. Now, I have almost no problems with telling people to slow down and this step made my experience of the illness more positive. Thus, one might complain that society is not well adjusted to the needs of people with a disability, but on the other hand by being creative and strategic one has the possibility to circumvent certain situations. In summary this discussion shows the interplay of agency and structure and demonstrates that people can use strategies in order to counteract stigmatization.

Conclusion and final remarks

This article has shown that the visibility or invisibility of a condition can have far-reaching consequences for people's lives and their social encounters. To come back to my initial question, the visibility of a condition does not necessarily lead to stigmatization. By playing out agency a person can slightly influence how he or she is perceived. Thereby, under certain circumstances, one can choose to which category one wants to belong; being disabled or passing as 'healthy'. This means people do not always conceal their condition to prevent negative consequences, but emphasizing their disability might also have advantages for them. Yet, one has to be careful not to assume that everybody at any time can choose between those categories. Most of the

time people do not have the opportunity to choose and the way they are perceived is strongly shaped by structure. Moreover, suffering from an invisible condition is not necessarily easier than having a visible condition. It just means that people encounter different difficulties. Disclosing one's invisible illness does not mean that the illness is visible to others. The fact that the illness is chronic and often particularly visible to people who are close to the sick person (family or a partner) for other people the knowledge that someone is sick may fade into oblivion. In this context it is interesting that visibility is connected to the moving body. Often only when a person is moving does the illness become visible to others, and by moving differently people are able to shape the visibility of their illness. Research about the body should therefore approach the body not as passive object, but as agentive entity.

To finish with some personal remarks, I often wondered why people were not considerate of my illness or did not help me when I asked for it. I believe that the invisibility of my condition plays a crucial role. Apparently it is difficult for people to realize that not every physical illness is necessarily visible. People seem to have the tendency to forget things of which they are not visibly reminded. Yet, I have to add that the necessity to be visible also depends on the cultural context. In Ireland, where I conducted my fieldwork, people were helpful and nobody refused to help me although people could not see that I was ill. In the Netherlands and Germany (where I am originally from) people are more reluctant to help when they do not see that anything is wrong. With regards to visibility, I think it is important to realize that there is more at stake than we can see. Scholars should pay more attention to the fact that people can shape how they are perceived and that visibility and invisibility are not strictly separated categories.

Notes

The author graduated in cultural anthropology at the University of Amsterdam. In her current research project, which is funded by ZonMw, she analyses how participation in reciprocal relationships shapes the illness experience of people with Multiple Sclerosis. The author is grateful for the valuable comments and suggestions of the reviewers and editors. Contact information: silkehoppe@gmail.com.

- 1 I have a chronic and progressive disease called Spinal Muscular Atrophy, which weakens my muscles.
- 2 To assure anonymity I used pseudonyms for my informants.
- 3 This is striking because in my current research project in which I interviewed twenty people with Multiple Sclerosis in Amsterdam, everybody who uses a wheelchair reports to have had this experience. This indicates a cultural difference in how people treat and perceive somebody in a wheelchair between Dublin and Amsterdam.
- 4 As this is in contrast to what Jones et al. (1984) suggest, this might indicate that suffering from a chronic condition nowadays might be less stigmatizing than in the past.
- 5 People who have Multiple Sclerosis can have balance problems that, when walking, make them look as if they are drunk.

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