The negative side of independence

An exploration of the self and others

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When I was diagnosed with a chronic and progressive muscle illness, my worst fear was of becoming dependent. I dreaded having to rely on others and not being able to do what I wanted to do. In order not to be or come across as dependent, I rejected people's help and would not ask for it. The price I paid for this independence, however, was high. In pushing beyond my physical borders, only because I did not want to ask for or accept help from others, I strained my body. Furthermore, rejecting help not only restricted me, but also offended others. Avoiding help and striving for independence is a phenomenon I recognize not only in myself, but also among other people who suffer from a chronic illness. However, little attention is paid to the negative effects that this can have. Based on my own experiences and on those of thirty people with Multiple Sclerosis whom I interviewed for my previous research project, I suggest how approaching dependency as part of reciprocity can be fruitful, both theoretically and practically. This article is an example of autoethnography, where shifting between the individual and the cultural leads to more insights.

[autoethnography, reflexivity, dependence, reciprocity, chronic illness, Multiple Sclerosis]

When I was seventeen years old I was diagnosed with an incurable and progressive muscle illness called spinal muscular atrophy.[1] Although I had realized long before that something was wrong with me, at that point my world fell apart. It was not so much the realization that I would have this illness for the rest of my life, but what scared me the most was the fact that it would only get worse and I would become more and more dependent. The evening I returned home from the hospital I swore to myself that I would never end up as a dependent cripple. This decision dictated my life for many years. I did everything to remain independent and categorically refused any help that was offered to me. In retrospect, I think I could have saved a lot of energy and frustration if I had not valued my independence so highly.

Relatively little is written about the negative consequences that striving for independence can have. But why do people want to be independent in the first place and what are the consequences of such behaviour? In this paper I will attempt to answer

these questions by analysing my own experiences with regards to my illness. Later I will compare my experiences to those of thirty people with Multiple Sclerosis (MS, an illness that in some aspects is similar to mine), whom I interviewed for my previous research project. Studying or writing about oneself, known as autoethnography, is not very common within anthropology, and is only done by a small number of anthropologists.

> Autoethnography is an autobiographical genre of writing and research that displays multiple layers of consciousness, connecting the personal to the cultural. Back and forth autoethnographers gaze, first through an ethnographic wide-angle lens, focusing outward on social and cultural aspects of their personal experience; then, they look inward, exposing a vulnerable self that is moved by and may move through, refract and resist cultural interpretations (Ellis & Bochner 2000: 739).

In autoethnography the personal is linked to the cultural (Ellis 2004: 37); the anthropologist becomes both subject and object (Callaway 1992: 43). Although it has been increasingly acknowledged that the anthropologist cannot remain objective, since both his or her sociocultural background as well as personality shapes anthropological knowledge production (Ahern 1999: 407; Riessman 2003: 6), there is still little space for the anthropologist, and especially his or her personal experiences, in scientific publications. However, within some schools of thought reflexivity and intersubjectivity have begun to receive increased attention (see Scholte 1972; Duranti 2010). Husserl introduced the concept of intersubjectivity in the beginning of the 20th century, but it only entered social sciences in the 1960s (Duranti 2010: 4). Intersubjectivity can be described as a shared symbolic space in which people create a shared reality (Tankink & Vysma 2006: 251), or where the self and the other interact (Duranti 2010: 2). Reflexivity, which has also received increasing attention, can be seen 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" (Rodgers 2002: 845). Thus, the anthropologist turns him- or herself into the object of analysis and focuses on his or her own motives, emotions, and struggles. Both concepts are analytic tools to become aware of how one influences the process of knowledge production.

Those tools are also important when doing anthropology 'at home'. Although anthropology began as a discipline studying distant and 'exotic' groups, analysing one's own people has become more common (Peirano 1998; Nguyen 2007). Following the argument of Reis (1998: 295), I define being at home not in terms of geographical place, but as related to shared experiences. Doing anthropology at home has several advantages. For example, the anthropologist speaks the informants' language, which can mean Dutch or English, or it can mean being familiar with a certain discourse or terminology, which in my case might involve EMGs (abbreviation for Electromyography), PBGs (Dutch abbreviation for personal budget), and CIZ (an organisation which determines the aid a person might receive). Moreover, the anthropologist might recognize certain emotions and experiences of his or her respondents.

On the other hand, doing anthropology at home can lead to certain dilemmas, which can make it difficult to maintain a distance from the research (see Tankink 2007; Nguyen 2007).

This project, in a double sense, is a case of anthropology at home. Not only was I geographically at home (in Amsterdam), but as I suffer from a similar illness I had also gone through related experiences. While it is important to remember that "we can never assume that the same experience produces the same experience" (Van der Geest 2007: 9), nevertheless one could state that the intersubjectivity between my inform- ants and me was 'intercorporal' (Merleau-Ponty 1964, in Coelho & Figueiredo 2003: 201), since to some extent we did share a body marked as sick and disabled.

In spite of the usefulness of reflection, intersubjectivity, and autoethnography, they often have a negative connotation. Reflexivity, for example, is sometimes confused with self-adoration (Babcock 1980, in Okely 1992: 2) or dismissed as navel gazing, being self-indulgent and narcissistic, or lacking a theoretical or methodological back- ground (Davies et al. 2004: 361). In line with Socrates one could conversely argue that "the unexamined life is not worth living" (in Roorbach 2008: 19), and that as a consequence, unreflective anthropological research is of little value. Furthermore, "in the study of human being by another human being (and what better medium is there?) the specificity and individuality of the observer are ever present and must therefore be acknowledged, explored and put to creative use" (Okely 1975: 172). Since dur- ing an interview people create a shared reality (Duncan 2004: 4), listening to a nar- rative also means taking an active part in its construction (Hydén 1997: 60). Thus the anthropologist can never be entirely objective and it is therefore better to reveal one's motivations and connection with the research topic because this can, and often will, influence anthropological knowledge production. Setting up qualitative research, according to Price, makes the author an "artist, interpreter, and composer" (1999: 1). Indeed, "we are always present in our texts, even when we write in so-called objective ways, attempting to obliterate ourselves altogether" (Davies et al. 2004: 365). Valu- able information might be lost when the researcher is not willing to look at his or her own emotions and motivations (Tankink & Vysma 2006).

Although the usefulness and necessity of reflexivity has been demonstrated, the question remains of *how* it should be done.

> There are few guidelines for how one goes about the doing of it, especially in a way that both is reflexive and, yet, notes the limits of self-reflexivity […]. The problem we face is much greater than the old puzzle of how we might be both the gazer and the object gazed at in the same moment (Davies et al. 2004: 361-362).

Just like our informants, as researchers we change our opinions, have good and bad days, and are maybe not always completely honest with ourselves. Those fluctuations have to be taken into consideration when analysing oneself. Reis (1998) points out that affective resonance and introspection can be used as tools to analyse one's data. Likewise, Lillrank (2002) argues that the scientist can only comprehend qualitative research data fully when the emotional dimensions of the interview are analysed.

In the following, I begin with a brief autoethnographic account and then link my own experiences to those of the people with MS whom I interviewed. I use introspection and reflexivity to analyse my experiences and to gain new theoretical insights. After I have reflected on my own experiences and those of my informants with regards to dependence, I will place them in a broader sociocultural context and suggest another way of conceptualizing dependence and independence.

Struggle for independence

When I decided not to end up as a disabled and dependent cripple I did not reflect very much on my motives. In order to understand my perspective on dependence it is important to first consider my upbringing. I grew up as an only child and my parents, who divorced when I was seven, were quite busy with their own lives. As a consequence, from a very young age I was brought up to be self-reliant and independent. In addition, when, for example, I asked my mother for help because I was afraid to do something, she often insisted that I do it by myself. Thus, even before I received the diagnosis, I was used to solving problems alone.

When I was diagnosed, not much changed. I was still used to doing things by myself, although this sometimes became more difficult. But what exactly did dependency mean to me and why did I consider it to be so bad? Even before my diagnosis, to be dependent for me meant not being able to do things by myself. If you cannot do things by yourself you are at someone else's mercy. You never know whether others will help or not, so better not to become too dependent on them. This perspective was closely linked to coming across as weak; another trait I tried fastidiously to avoid. Once I was diagnosed with the illness, more specific reasons appeared. For example, I refused help in order to prove to myself that I would still be able to do things, like getting up from the floor by myself after falling. Although I did not realize it back then, I believe that in addition I did not want to be a burden to others. Moreover, receiving help meant giving help in return, and because of my illness I had the feeling that I would need more help than I could pay back and thus it would be better to avoid it completely. I did not want to feel indebted to people who helped me. One could say that with regards to my illness I was not willing to reciprocate. In retrospect, I do not fully understand why I did not want to feel obliged to help others, but my guess is that it had something to do with my desire for freedom and independence.

Whether my reasons were valid or not is irrelevant, but it is important to focus on the consequences of my 'lust for independence'. First of all, in doing everything by myself and refusing to ask for or accept help, I strained my body beyond its boundaries. As a result I was often exhausted and had to spend hours in bed recovering. Second, this behaviour was not beneficial for my relationships. If one compares offering help to offering a gift, rejection is normally not appreciated by the giver (Schwartz 1996: 71). Hence people felt offended when I refused to accept their help. Wanting to come across as strong and independent might be good in a professional setting, but with your friends and family you appear rather distant and unapproachable. When you

do not show that you are vulnerable others often do not share their feelings either, and thus an important aspect of friendship, namely helping each other in difficult situations, is made impossible.

What made me finally change my attitude towards dependency? One important aspect was time. Fighting dependence had become a kind of lifestyle and habit. When you are used to approaching life and the problems related to it in a certain way you cannot easily change this. Approaching my life situation in another way took me several years. I slowly realized that my behaviour would only make me unhappy, and as my condition would not improve I should find a different way to deal with it. Striving for independence not only overstrained my body, it also made me feel lonely, since repeatedly rejecting help can have negative consequences for social relationships, while giving people the opportunity to help can deepen and strengthen relationships. Indeed, most people like to help and do not see it as a burden. Moreover, accepting help can also create freedom. If people help you, you can save energy for things that you would like to do, instead of proving to yourself and others that you are independent. Another factor that shaped my attitude was the people around me. More and more people told me that I should respect my own boundaries and not be so stubborn.

During my fieldwork I encountered some people who, in my opinion, just like the earlier version of me, paid a very high price for their independence. I especially remember the case of 46 year old Thomas.[2] When I went to his house in order to interview him, he still had not returned home as his transport service had been delayed. When he arrived in his push wheelchair I followed him to his house, where a small ramp bridged the step to the door. A small step remained, however. He tried a few times to get his wheelchair up the ramp to open the door, but failed to do so. Eventually, he handed the keys over to me and asked me to open the door. It felt a bit awkward having the keys of a stranger's house in my hands. I thought that if I wanted to I could rob his house and he could do little about it. When I opened the door, he still could not manage to get his wheelchair across the doorsill. I was a bit hesitant to push the wheelchair as I too do not have much strength in my arms and legs, but in the end I pushed his wheelchair and together we managed to enter.

Seeing Thomas struggle to get into his house, I felt astonished that he had not had the door adjusted. Why did he prefer to be, in his own eyes, independent, rather than able to enter his house comfortably? Why did he expose himself like that? I imagine that if I were in the same situation I would have felt humiliated, because although I now accept help more easily I still do not like to come across as dependent. To be seen to try something without success is, for me, even worse than asking for help. Maybe he felt similarly about it, or perhaps he could generally avoid it because normally few people saw him entering his house. During our conversation I raised the issue and discovered that he also had problems getting the key into the keyhole, because his illness affects his gross motor skills. I asked him why he did not arrange for an automatic door opener. He explained that his motto is to postpone any kind of help and to manage everything by himself for as long as possible.

Another time I interviewed a man who lived on the second floor, but who, just like me, had problems climbing stairs. In fact it tired him so much that he hardly left

the house. Only after accepting the situation for years did he decide to ask the city council to arrange for a ground floor apartment. Although I could understand that he did not want to leave his old house, I was still puzzled by the situation. If he had been fighting with the city council in order to get an accessible home but did not succeed, I would have understood. But as with the case of Thomas I did not fully comprehend his behaviour, as not wanting to ask for help actually resulted in a greater degree of dependence. On the other hand, somewhere within myself I also recognized the feelings of wanting to do everything by myself and as a consequence feeling exhausted but also proud and satisfied.

Similarly, in many interviews people expressed that they preferred not to depend on others and therefore did not want to ask for help.

> I want to be autonomous and I prefer not to be helped by others. I just don't want to depend too much on others (Esther, 43).

> I guess being dependent is the worst thing that can happen to you. I think this is true for everyone who is dependent. It is just like someone who has to beg, that person is also very dependent. I just think it's very difficult (Lotte, 67).

> I try to be as little dependent as possible (Maarten, 55).

When I asked for their reasons for not wanting to be dependent, some people said that they did not want to burden others.

> The worst thing is to depend on someone who has to give things up for you although there is health care. So when it is necessary I will use it so that my wife can keep her job (Jan, 46).

Others just wanted to do as much as possible by themselves in order to retain a positive self-image.

> I like to do things by myself because of the independent feeling. It's all about self-worth (Thomas, 46).

Asking for help, however, makes a difference for those on whom people depend. In order not to strain their relationships, some preferred to hire a carer to take over certain tasks. In this case, one could argue that help becomes more like a consumption good (Wilson 1993: 51) and is therefore easier to ask for.

One could say that during the interviews I met many earlier versions of myself, which felt strange and also painful. I wanted to tell these people to stop striving for independence at any price, and to help them realize that their desire for independence actually restricted them and in some cases made them even more dependent. I was also reminded of my own struggle with asking for help, and how that had changed over time. One advantage I had was that I had moved around and lived in different

places, so that the people in my new situations saw the current and not the earlier version of me. Thus, I had been able to change more easily. But for someone who is already over fifty, for example, and has refused to ask for help his whole life, he might find it extremely difficult to change his attitude when illness enters his life. As I believe that everyone has to find their own path, I did not express my opinion explicitly. I did, however, make some small remarks regarding the fact that I also found it hard to ask for help, but that it definitely makes life easier.

However, several informants did also seem to have changed their views on independence. Many emphasized that accepting helping devices or transport aid was difficult in the beginning, but that after they had overcome that boundary they realized that they were actually much more independent. For instance, instead of waiting for her husband to do the groceries, one woman told me how happy she was when she was finally able to go shopping in her electric wheelchair.

> When I got the thing [the electric wheelchair] I thought, well I am not fifty years old. But then I thought, well I just get in it so that everybody sees me and then I am done with that. So I went to the station to pick up my husband and then people said 'Oh that's pitiful'. But I replied, 'Pitiful? Well, at least now I am more independent. I can do things by myself and I don't have to ask you anymore if you push my wheelchair or do the groceries for me' (Irma, 59).

Similarly, another woman discovered a new world once she accepted to use the wheelchair outside her house.

> A whole new world opened for me when I decided to use the wheelchair outside of my house. Simply being able to buy fresh vegetables at the market was terrific. I now go everywhere with it. In retrospect I regret that I did not do so earlier (Esther, 43).

Others also stated that they had become more accustomed to asking for help.

> I do everything what I still can do and if I need help, I ask for it. It has become easier for me to ask for help. In the beginning I would never ask for something and just continue and continue. Now, if I can't do something, I ask for help. I am more easy-going about it now (Jan, 46).

> It changed. In the beginning I found it very difficult to ask for help, because I still think I can do everything, it only takes me longer. Ten years ago I didn't accept any help. Now it's more in balance, although if you asked my girlfriend she would say that I still reject too much help (Thomas, 46).

> It is still difficult, but you learn gradually. But still you want to do as much by yourself for as long as possible (Erik, 38).

Although several people stated that through the illness they had learned to ask for help, some also expressed that because of their illness they tried to ask for less help.

> Well, if you'd ask my daughter, she would say that I never ask for help. I kind of learned to ask for help, but I prefer not to. Maybe this is because of my illness, but I just have the feeling that I have to do things by myself (Lotte, 67).

> I think that now I would less quickly ask for help, because I want to prove to myself that I can do it (Sylvia, 34).

I have not had the exact same experiences as my informants, yet there are several aspects in their stories that I recognize. I have tried to show that my 'lust for independence' is not an individual problem, but something that many people have (and are possibly being restricted by). In fact, doing research among people with a similar illness made me realize this. Whereas before I thought I was special because I was so terrified to ask for help, during fieldwork I recognized that it is something that many people struggle with. Finally, my anthropological training made me think very differently about independence and dependence.

Through the anthropological looking-glass

From a broader anthropological perspective it does not seem surprising that people in the western world prefer to be independent. After all, independence is depicted as something desirable and dependence has mostly negative connotations (Robinson 1988: 62). Kerry and Meyerson state that "independence, self-sufficiency, self-direction, and self-interest are as typically American as the flag, motherhood, and apple pie" (1987: 193). In the last decades, more and more emphasis has been placed on independence and self-reliance (Shakespeare 2000; Breheny & Stephens 2009). This is reflected in public discourse, politics, and the media. It is believed that independence is important to maintain self-identity and self-respect (Circirelli 1992, in Wilson 1993: 47). Independence and self-reliance are depicted as necessary skills in order to survive in our western society. But what exactly makes independence so desirable and what is it that is culturally admired in it? The desire for independence is probably connected to the individualization of western society (Brannen & Nielsen 2005). Furthermore, it is connected to the idea of power. Being self-reliant increases your chances to do what you want to do, and if you depend on others, your power is limited.

Dependency is something a lot of people are afraid of. "Previous studies have found that being dependent on others is one of the greatest fears of older adults and that maintaining independence is a goal that has been rated as integral to their quality of life" (Gignac et al. 2000: 362). Disabled people are often perceived as being needy and dependent (Tronto 1993: 210, in Shakespeare 2000) and one could say that being sick involves multiple forms of dependence, because all of a sudden one has to rely on partners, friends, doctors, or other services that one would not normally

need (Nijhof 2001). This does not mean, however, that other people are not needy or dependent. Through analysing my own experiences and those of my informants one could argue that our fear of dependence derives from a general societal trend. Social scientists and health care workers often point to the negative consequences of impairment and physical dependence, for example a restriction in social activities, lower self-esteem, and failure to fulfil one's social roles (Buunk & Schaufeli 1999: 271-272). Independence, in contrast, is said to increase one's quality of life (Wilson 1993: 48). But (the desire for) independence can also have a negative connotation, if it "implies what relatives or professionals may feel is a 'pig-headed' refusal of 'necessary' services" (ibid.). Such refusals could, however, actually "represent an effort to escape from the 'smother love' of overprotecting people who maintain their own self-esteem by helping others 'less fortunate than themselves'" (Kerry & Meyerson 1987: 179).

It is important to remember that no one is independent. Everybody depends on others in order to eat, work, and survive (Shakespeare 2000). Furthermore, "most of us are deprived if we are not allowed to forge and maintain certain important bonds in our own way" (Williams & Wood 1988: 131). Or as Kerr and Meyerson argue, "human beings are social animals, and the rigidly independent person will inevitably be isolated and lonely" (1987: 173). As social beings we depend on social relationships, which involve a certain degree of dependency. This is not only true for people with a disability, but for every human being.[3] "As anthropologists have pointed out the single greatest gain of our early ancestors in becoming human was in developing and institutionalizing the dependency relationship" (ibid.: 174). Thus one could even argue that our modern society is structured upon the principle of dependency.

It is interesting to note that dependence is not always considered as something negative. There are differences with regards to different groups of people, but also with regards to time. The fact that children are dependent on their parents, for example, is considered normal (Fraser & Gordon 1994: 309), and for a long time a housewife dependent on the income of her husband was not seen as unusual. Having a chauffeur, housekeeper, personal maid, or secretary is also not seen as undesirable (Kerr & Meyerson 1987: 175). Thus a certain kind of dependence, for example on your mobile phone, GPS system, or secretary is socially acceptable. Moreover, dependence in certain circumstances is related to higher status. Someone who does not need to prepare his or her own food, is driven around by someone, and has enough personnel to take care of his or her needs, could on the one hand be disabled, but could also be part of the royal family (Shakespeare 2000). If we go back in time to the beginning of the 20th century, dependency was associated with trust and reliability. Only with the rise of post-industrial society did dependency lose its positive connotations. Indeed, "The 1980s saw a cultural panic about dependency" (Fraser & Gordon 1994); the Dependent Personality Disorder was introduced as an official disease and more attention was paid to different kinds of addictions. Reflecting on this discussion, one could argue that the fear of dependency is exaggerated and unnecessary. Yet, in reality I have not talked to anyone who placed his discomfort with dependence in a broader context and emphasized that actually we are all dependent.

The question thus remains as to when dependence is considered good and acceptable and when it is not? Certainly it is important on whom, when, and on what one depends. It seems that choice plays an important role. The rich man, in society's eyes, can choose whether or not to have servants. The disabled person, in contrast, would possibly not survive without the help of a carer. Moreover, the wealthy person receives a high status based on his or her work or family line; an expensive car, a big house, and high job position furthermore arouse appreciation. The stereotype of the disabled person, in contrast, is of someone who cannot work and depends not only on the help of others but also on the state and thus on society's taxes. Although I personally do not agree with this view and I have depicted the situation in a stereotypical manner, I believe that many people perceive the situation in this way. Furthermore, it seems that there is a hierarchy with regards to physical, social, and psychological dependence (Kerr & Meyerson 1987: 174). People who are physically dependent have a lower status than those who are psychologically or socially dependent. But if we continue to approach the situation in this way nothing will change. Therefore in the next part I will suggest a way to analyse the situation of people with a disability, not in terms of dependence or independence but in terms of participation in reciprocal relationships.

An alternative concept

As I have demonstrated, independence is a problematic concept; not only because it is a myth but also because it implies that people should be able to do things by themselves and be self-reliant (Morris 1993: 22). Different scholars point out that instead of talking about independence, one should focus on autonomy or agency. Cardol et al. (2002) argue that when addressing the situation of people with a disability or chronic illness, it is important to make a distinction between decisional and executional autonomy. As Kerr and Meyerson (1987: 175) state:

> By definition a person with a physical disability lacks adequate tools for certain physical behaviours, but there is no necessary relationship between those missing or impaired physical tools and the ability to meet the demands of higher social, psychological, and cognitive tasks.

Autonomy is therefore not strictly equated with physical independence. But in practice this often happens. Lotte, for example, equals independence with 'doing things by yourself':

> Independence is the highest good for human kind, the most important thing. Independence means that you don't have to ask things from others (Lotte, 67).

However, another informant was very aware of the difference between autonomy and physical independence:

> I think people at the regional coaching [which is provided by a nurse specialized in MS] do not explain well what self-sufficiency means. Because of course you want to be as independent as possible, but let's pick an example. I cannot grab anything from that cupboard because I am sitting in a wheelchair and I can't reach it. But I would be independent if I asked you if you would get it for me. This is also independence. It is not because I am needy, but if I ask you to help me get into my jacket I am autonomous because I put on the jacket at the time that I want to. If I need help putting on my jacket, it's no point, because I say when it happens and which jacket I put on. So there is a big difference in the interpretation of what it means to be independent (Irma, 59).

Instead of focusing on whether or not somebody can do something without assistance, the emphasis should be on whether the person can make his or her own choices without being restricted. "An important product of decisional autonomy is self-realization: the ability not only to make choices freely and independently, but also to shape one's life into a meaningful existence which expresses individuality" (Cardol et al. 2002: 972; see also Wilson 1993: 49).

Although the concepts of decisional and executional autonomy seem more useful than the concept of independence and dependence, they still have some shortcomings. Not enough attention is paid to the relational aspects of human existence. People are social beings and should therefore not be conceptualized as 'atomistic individuals' (Sevenhuijsen 1998, in Shakespeare 2000). The concept of interdependence places more emphasis on social relationships. "Inter-dependency is a characteristic of human life, not an aberration associated solely with illness or disability" (Cardol et al. 2002: 971). One can argue that people are always moving along a continuum of independence, dependence, and interdependence (Kerr & Meyerson 1987: 177). From this follows that people are not dependent or independent, but shifting constantly between extremes; in one setting or time one is dependent on others, in another one is not. Thomas, for example is very independent at his work and the business could not run without him, but with his family, friends, or girlfriend he feels more dependent.

> At my job I am equal. People appreciate what I do and one could say that they greatly depend on me. But this is a problem with family and friends, because for example you go to a restaurant and then you're confronted with your handicap because you have to look for an accessible one. Also many discussions then focus on me having a disability whereas I would just like to talk about politics or the weather (Thomas, 46).

Although the concept of interdependence is useful because it focuses on the interconnectedness of people, it too has shortcomings because social relations are insufficiently analysed. In contrast, the concept of reciprocity places a strong emphasis on and also explicitly deconstructs people's relationships with each other. According to Mauss (1990: 50), reciprocity is built on three obligations, namely giving, accepting, and returning. It can be defined as "the equality of one's perceived investments in and benefits from an exchange relationship relative to the person's own internal standards regarding this relationship" (Schaufeli 2006: 93). In other words, it is the "social glue

that holds groups and societies together" (Zhang & Epley 2009: 786), since through reciprocity people form bonds and one could argue that it keeps society together. "The interaction and interconnectedness of individuals are what constitutes the social fabric of all social institutions, what constitutes society" (Brannen & Nielsen 2005: 426).

It is important to keep in mind that what matters is how people perceive those exchanges and not necessarily whether they are really in balance (Ybema et al. 2002: 79). Through those forms of exchange social relations (Lévi-Strauss 1964, in Dwyer et al. 1994: 35) and trust (Mauss 1990) are created and sustained. Thus, one could argue that it is not dependency but nonreciprocal relationships that are problematic (Wilson 1993: 46).

> I think you would more quickly feel guilty if you have to ask for help but cannot give something back. But luckily I am not in that situation (Sylvia, 34).

Ria, who is 53 years old, phrased the role of reciprocity with regards to dependence as follows:

> To be independent in a certain way, yes, I like to make my own choices, to be autonomous as I call it. But I know that I am never completely independent. I mean, I am dependent on the woman that comes every week to help me. I am dependent on a lot of things. But it has to be in balance. It should not become a too large part of your life. To be dependent and to have to ask for help is especially annoying if you are never able to return something. Thus, if I ask my friend whether she can drive me to the IKEA, because I want to buy some new furniture, I know that she really appreciates chatting with me. And this is really important for me, because I then know that she also benefits from our meeting. Practically, I cannot do so many things, apart from buying flowers, but I know that I can be there for her emotionally. Thus, first and foremost it is important that you have the feeling that you yourself have something to offer. If you don't have that, it's much harder.

Rather than focusing on independence and dependence we should shift our focus to the concept of reciprocity. Another advantage of the concept of reciprocity is that it implies that exchanges do not happen directly, but can take place after a variable degree of time (see Pound 2011: 198). Furthermore, physical assistance can be 'paid back' with emotional support. As Kleinman (2010) has pointed out, caregiving is not simply a burden, since it can also make life more meaningful: "The actions of caregiving create the emotional foundations of solidarity, for sustaining responsibility" (ibid.: 18). He states that through caregiving he witnessed a radical transformation of himself. Thus one should not forget that giving fulfils people and makes them happy. In addition, it strengthens relationships among people and creates trust. This makes the concept especially valuable for people with a disability who physically might not find it easy to return favours.

Concluding remarks

In this article I have argued that striving for independence is a myth that can bring more harm than benefit. In contrast, by asking for help one can actually gain freedom and independence. It should be emphasized, however, that being dependent or independent is not a personal trait, but something that is part of life and changes constantly. Depicting people with a disability as dependent is therefore not accurate and undermines everything that they contribute to their family and friends as well as to society in general. Thus, it is important for people who work with the disabled to keep in mind that they should not place too much emphasis on independence. I could not say it any better than Kerr and Meyerson (1987: 174):

> Independence is not the essence of being human, nor is it a royal road to love, happiness, satisfaction in living, or mental health. Let us not, therefore, overemphasize for people who have disabilities a monolithic but disabling goal that glorifies an inappropriate, sometimes harmful, myth of independence.

The discipline of anthropology in particular could benefit if more attention is paid to the interconnectedness and interactions of people. Moreover, reflection and introspection are valuable tools for anthropologists, which can lead to more insights. In my case, the link between my research interest and own background is obvious and it would seem unnatural to separate the different ways in which anthropology, self-exploration, and personal experience are connected. My personal life has affected my research specialization and theoretical perspective. Based on my own experience, I felt that there are many false perceptions about suffering from a chronic illness and I wanted to depict a different picture.

One could argue that my 'experience knowledge' has had many valuable advantages when doing fieldwork. I have the impression that it has been easier for me to find participants for my research projects, that people talk more openly to me because they feel that I have been through similar experiences (although of course this is not always the case), and that because of these experiences I am more sensitive to certain critical topics and can perhaps 'dig deeper' when I think it is necessary. Of course there are also certain dangers involved. One has to be careful not to make generalizations based on one's own experiences. In addition, people who know that the person interviewing them has had similar experiences might be less explicit in their answers because they suppose that the researcher already knows what they mean. The experiences that I had during fieldwork in turn shaped my personal life. I have used anthropological insights to gain a deeper understanding of my own situation. I realized that my own feelings and experiences were common among others who suffered from a similar illness and I could place them in a broader context. In particular, my introduction to the concept of reciprocity made me strive for balanced relationships instead of independence.

Zooming into my personal experiences and then looking through the ethnographic wide-angle lens made me think in more general terms about anthropological research. During the writing of this article, I constantly remembered things that I had not men-

tioned in earlier drafts and I also realized that I might have presented myself too idealistically. Even today I still prefer to be independent and when offered help I do not always accept it. This lays bare a particular challenge of anthropological research: people constantly change how they think about themselves and others. Thus, it is important to follow people over time and build personal relationships with informants. People who share similar experiences with their informants might be particularly skilful in doing this (see also this issue Hesebeck). In addition, comparing other people's experiences to one's own helps to place those experiences within a broader context and gain deeper insights. As Tankink (2007) suggests, anthropologists, like psychotherapists, could benefit from receiving a kind of supervision, which "helps the anthropologist to become aware of his or her own motives, needs and processes" (ibid.: 143).

To conclude, in this paper I have aimed to demonstrate how my personal life, anthropology, and self-exploration are intertwined both in my research and on a daily basis. I demonstrate how reflecting on my own situation not only provided me with deeper insight, but also advanced my theoretical understanding of dependence, independence, and interdependence, which in turn directed me to bring in a new concept altogether, namely that of reciprocity.

Notes

1 I have a mild form of Spinal Muscle Atrophy, which means that I have problems climbing stairs, walking for long distances, and tire more quickly than a healthy person.
2 To assure anonymity I use pseudonyms for my informants.
3 From a disability studies perspective one could argue that dependency is often caused by social relationships and the wider context. Inaccessible buildings and public transport, for example, make people with a disability more dependent, and they would become less dependent if the disabling environment was changed.

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