

Chronic Illness as a Source of Happiness

Paradox or perfectly normal?

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Abstract

In this paper I analyse the relation between happiness and chronic illness from the perspective of medical anthropology and disability studies. By looking at the disability paradox I deconstruct society's view of people with a disability. I argue that the disability paradox is problematic as it ignores the views of people with a disability. Moreover, such a paradox reinforces the idea that living with a chronic illness or disability is a devastating experience and that happiness and disability are mutually exclusive realities. Based on empiric examples of people who suffer from Multiple Sclerosis I demonstrate that people with a chronic illness can experience happiness in spite of illness, but also as a consequence of it.

Keywords: *chronic illness; disability; happiness; disability paradox; Multiple Sclerosis*

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I. Introduction

When I ring at Sarah's doorbell for an interview the door opens automatically. I shout 'hello' and enter carefully. A voice guides me into a sleeping room where I see Sarah lying in a medical bed. Sarah has Multiple Sclerosis and as a consequence needs to rest in bed the majority of the day. As she has eight carers, she can still live at home. Having worked as a medical doctor for many years, she immediately suspected that she had MS. With the progression of the illness, her life became more and more restricted. She had to stop working and give up many hobbies. Notwithstanding she says that she is pleased with her life. Friends regularly stop by for a visit and she can still go out in her electric wheelchair to join family meetings or to buy an ice cream in the summer. Furthermore, with the slow progression of the illness she had time to adjust to the changing circumstances. This does not mean that she is happy all the time, she also complains about the carers who forget to put her telephone in her reach or people who stare at her when she is in the wheelchair. But overall she emphasizes that she leads a good life.

After leaving the interview I feel confused. On the one hand I feel sorry for her, because she had such an active lifestyle and now has to rest in bed most of the time. On the other hand, I doubt whether she is as happy as she says she is.

What I experienced could be described as the disability paradox, where people with a severe disability reportedly have a good quality of life. The thoughts that I have after the interview reflect how I have learnt to think about and perceive disability and chronic illness; namely as something undesirable and terrible.

Albrecht and Devlieger (1999) who analyzed the paradox define it as follows: "Why do many people with serious and persistent disabilities report that they experience a good or excellent quality of life when to most external observers these people seem to live an undesirable daily existence" (Albrecht & Devlieger, 1999: 977). In this article I analyze the relationship between happiness and disability arguing that the disability paradox is problematic in that it ignores the views of people with a disability. By assuming that health is the major factor and constitutive measure influencing someone's quality of life, such a paradox can only serve to reinforce the negative view 'healthy' people have of people with a disability or chronic illness. In this article I will further demonstrate how this disability paradox indeed reflects people's perspective on people with a disability. Through a truncated literature review I will deconstruct how scholars have approached happiness and chronic illness and how Western society views this relation. After discussing the research methodology employed for the present study, I will present empirical examples, which draw upon the viewpoints and experiences of people who have a disability.

Research design and methodology

Our present study is based on a case study of people who suffer from Multiple Sclerosis. Multiple Sclerosis is a disease of the central nervous system, which leads to the progressive loss of bodily functions. The main symptoms are numbness; problems with coordination, balance and speech; pain; fatigue; stiffness, incontinence, and muscle weakness. Neuropsychological problems such as the lack of concentration; oblivion, and disturbed self-perception can also result from, and/or be indicative of Multiple Sclerosis. It is a progressive disease most common among young and middle-aged adults, the exact cause of which remains unknown as does a cure (Ghaffar & Feinstein, 2007; in Pakenham & Fleming, 2011; Thompson & Hobart, 1998).

Four months' fieldwork was undertaken in Dublin and six months in Amsterdam. The aim of the research was to study as to how people experience illness. Purposive sampling was used in order to find informants. I approached in total twenty-two people with MS through the national MS society in Dublin, and thirty in Amsterdam. Half of the informants were interviewed more than once. The participant age ranged from mid-twenties to late sixties. Half of participants were men, and half women. The participant sample consisted of people from different socio-economic backgrounds and of varying educational levels. All participants were classed as 'white' citizens. Participants presented different forms of MS and severity of the illness was variable.

Qualitative research methods were applied consisting mainly of semi-structured interviews. The duration of interviews was one to four hours, during which time the focal point was personal experience of illness. The conversations took place in the family homes, in a care center or in a café. All interviews were recorded and subsequently transcribed. All participants were informed with regard to the aims and objectives of the research. To assure anonymity pseudonyms are used for all participating informants.

II. Health, Happiness and Chronic Illness

"Happiness is a positive emotion or feeling of satisfaction" (Marinic & Brkljacic, 2008) – it can be defined as the degree to which a person evaluates his or her life as positive. Happiness is thus a subjective concept; the person concerned decides whether he or she considers his or her life as worthwhile from within, and it cannot be ascribed objectively from without (Diener, 2000). Happiness is considered to be an important aspect of life yet a life of only happy moments is also seen as empty or superficial, for it is not happiness alone which we want to experience (Nozick, 1989). Although happiness is a concept, which has driven the meditations of poetry and philosophy, it was only with the development of positive psychology in the late twentieth century that systematic and scientific analyses became more commonly applied to investigation (Marinic & Brkljacic, 2008).

If we look more specifically at this relation, we see that for a long time the focus had been on everything but happiness. For many decades the focus lay on illness, deficiency and impairment (Meyers, 2000). In the 1980's predominant themes of suffering (Charmaz, 1983), loss (Duval, 1984), biographic disruption (Bury, 1982), and the sick role (Stewart & Sullivan, 1982) were common pillars to enquiry. Attention was given to the negative consequences resulting from living with a chronic illness; people may experience a loss of self as their body loses its functions (Charmaz, 1983, 1991, 1995); their self-worth and identity are assaulted (Bury, 1982); people have to resultingly face isolation; dependence; marginalization; exclusion (Ware, 1999); stigmatization (Jacoby, Snape, & Baker, 2005; Susman, 1994); unemployment; financial insecurity; depression or even suicide (Thompson & Hobart, 1998). The picture, at times a true one, was nevertheless bleak.

A decade later, scholars began to approach chronic illness in a more positive and affirmative way. Thorne and Patersson (1998) questioned whether chronic illness was in fact no longer seen as devastating or whether it had

become politically more correct to shift from a problematic view in which chronic illness is seen as a terrible experience to one that includes joy as well as sorrows. Research thus began to progressively concentrate on themes such as courage and hope; the reshaping of the self; the regaining of control; the discovery of meaning; the empowerment of potential; and normality (Thorne & Paterson, 1998). However, instead of presenting a complex picture of the situation of people with a chronic illness, certain scholars sooner sought to “overemphasize the cheerful, existentially transformative, and powerful elements within that experience over the mundane and ordinary features such as pain, mobility impairment, anxiety, or despondency” (Thorne & Patterson 1998: 176). And by merely underlining only the positive aspects of living with a chronic illness, the chronically ill person became an idealized personage.

Disability Studies witnessed a similar trend: focus was quick to shift from the medical model, in which the disabled individual was seen as problematic to the social model where society itself was seen as the cause and condition for disability (Oliver, 1990). Disability studies scholars no longer sought to approach a person as disabled by the absence of, for example legs, but by the fact that society failed to adapt to the needs of wheelchair users. The social model of disability proved an important contribution to changing how we think about and perceive disability, yet disability itself was at risk to become a trivialized phenomenon where individuals who struggled with their situation were given little consideration. Consequently, by shifting the focus from the individual to society, all bodily experiences such as pain and fatigue were ignored (Williams, 2001).

In the context of disability studies, the disabled person is often portrayed as a hero or ‘supercrip’, someone who displays a lot of courage and is determined to overcome the disability (Black & Pretes, 2007). Yet, “while prodigious achievement is praiseworthy in anyone, disabled or not, it does not reflect the day-to-day reality of most disabled people” (Shapiro, 1994: 17; in Black & Pretes, 2007: 67). Moreover, the measure of prodigious achievement in creating the heroic and successful can equally qualify failures. As Eisland (1994) states: “living with a disability is difficult. Acknowledging this is not a defeat, I have learned, but a hard-won accomplishment in learning to live a life that is not disabled” (Eisland 1994: 13; in Kool, 2010: 257).

The emergence of the disability paradox is synonymous with the academic tendency to shift focus from the negative to the positive. Freedman (1987) was the first who described people with a severe disability who express a high or extremely high quality of life, arguing that many experience happiness from the ability to deal with their condition (in Albrecht & Devlieger, 1999; Marinic & Brjljacic, 2008). Weinberg (1988) similarly found that people with a disability who are able to reach their goals attain a personal satisfaction (in Albrecht & Devlieger, 1999; Marinic & Brjljacic, 2008). Albrecht and Devlieger (1999) further analyzed the paradox asserting that people who are able to establish a balance between body, mind and spirit and do not experience pain, fatigue or loss of control, report having a higher quality of life. For Albrecht and Devlieger, the disability paradox exists in two ways. Firstly, people with disabilities report having a high quality of life in spite of several restrictions. Secondly, the general public, including physicians and health care workers, assume that people with disabilities have a low quality of life despite the fact that people with disabilities themselves typically disagree with this statement (Albrecht & Devlieger, 1999).

There are several studies confirming the disability paradox and report that people with disabilities claim to have a high quality of life (e.g. Kutner et al., 2003). Likewise does there exist research, which is more sceptical, casting doubt on whether people with a disability really have the high quality of life they attest to. Mehnert et al. (1990) found that people with disabilities have a lower life satisfaction, especially those suffering from multiple disabilities. If we look specifically at Multiple Sclerosis (MS), different researchers have pointed out that people with MS experience a lower quality of life in comparison to the general population (McCabe & McKern, 2002) and are more likely to report psychological distress (Ryan et al., 2007), including anxiety and depression (Uguz et al., 2008).

In analyzing how chronic illness and disability have been studied, we can equally observe different tendencies, given that, “historically, health care and health service researchers have paid little attention to happiness” (Meyers, 2000: 342) the attention to loss, dysfunction and deficiency has signaled a lack of holistic and integral focus. This oversight to the positive aspects and attention to deficiency has received criticism within disability studies as well as other disciplines (Mehnert et al., 1990; Sunderland, Catalano, & Kendall, 2009). Yet, while some scholars identified that living with a chronic illness or disability is more complex, others fell into the fallacy of over-idealizing the experience of illness and disability. In the arena of research the oscillation between the simple and complex as well as the negative and positive, is telling.

But in how far is this shift reflected within the broader context of society as a whole wherein negative representations of people with disability predominate (Sunderland, Catalano, & Kendall, 2009)? As has been asserted: “The general population has consistently expressed negative attitudes towards people with disabilities and do not think that they have a very good quality of life” (Wright, 1988; Brillhart, et al 1990; in Albrecht and Devlieger, 1999: 982). There is seemingly a missing discourse of joy and happiness in relation to disability, which carries with it behavioral codes of the pitiful, needy and unhappy (Sunderland, Catalano, & Kendall, 2009). Furthermore, society uses disabled people as scapegoats and accuses them of being ‘different, expensive, inconvenient or odd’ (Shakespeare, 1994) and in the most extreme of cases, as a threat to the image of the strong, independent and fearless human being. Jenny Morris, a disabled feminist asserts:

The messages we receive are very strong and clear and we have little access to different values which may place a more positive value on our bodies, ourselves and our lives. Our self image is thus dominated by the non-disabled world's reaction to us' (Morris, 1991: 28; in Shakespeare 1996).

This view is the result of a ‘collaborative effort’ of people without a disability (Meyers, 2000: 345).

It is not that we are forbidden to talk about joy and happiness in relation to people with disability, but rather that we are either (a) incapable of seeing or talking about joy and happiness in relation to disability because there is nothing in public discourse or our own experience to suggest it or (b) we have turned our face from the negativity and sadness attributed to disability to such an extent that we do not see people with disability at all (Sunderland, Catalano, & Kendall, 2009: 705).

Thus one can ask, as to why it is such an obstructed task for us to imagine that people with a disability or chronic illness can be happy (Meyers, 2000)?

III. Happiness in the Field

Happiness in spite of illness

Sarah, whom I mentioned in the introduction is fifty-seven years old, lives in Dublin, and was diagnosed with MS at the age of twenty-four. For many years the illness only had a minor effect on her. About ten years ago the illness worsened however, and she had to use a stick and crutches for walking. Now she has to rest a lot and can only move around in an electric wheelchair. Sarah emphasizes that she handles her condition well:

I suppose I am well adjusted to it. I don't have a different outlook on life. I channeled my interests into other things. Rather than sports and exercises that I used to do, I do other things now. I used to like going out for meals, but I don't like it now because I have to be fed. I like to listen to the radio a lot.

Sarah continues to receive many visitors and is grateful for the support expressed by her friends: "I suppose positive things are that I realized who my friends are really. They have done wonderful things and have helped me a lot. You see good things, people in general are very nice, particularly when you are in a wheelchair". Yet although Sarah expresses contentment with her friends, she is less happy with her carers and society in general:

I think people are inclined to think you don't have a life, just because you are in a wheelchair. People [carers] wouldn't make an appointment, they would just come. But one day, three of them came and I just was out and said 'sorry I can't wait, you have to make an appointment' and then they were kind of surprised. That's good. There are some people I know who don't go out anymore. But I still like to go out a lot.

Although Sarah depends on eight carers she still plans her life independently and has adapted well to her illness. If she cannot do something due to her illness, she tries to find an alternative activity, which she can still enjoy. In spite of her physical restrictions she comes across as a happy individual who enjoys life. This does not mean that it is easy for her to deal with her illness for there are moments of struggle with her condition. These moments of struggle do not act, however, as obstacles to her regular experience of happiness.

Another informant who states that she is well-adapted to her illness is Anna, who is thirty-five years old, single, and also lives in Dublin. She was diagnosed with Multiple Sclerosis in 2003 and works fulltime in a disability organization. Her symptoms include fatigue; incontinence; balance problems, and a general weakness. Anna uses a walking stick for short distances and a wheelchair for long distances.

I think meeting someone, meeting a partner would be the biggest thing. I am really sorry I didn't have a man in my twenties. The realization is hard, and it's a lot harder now. Because you're bringing the MS into their lives. It's harder. I would be more hesitant letting somebody in. It's not a huge issue or something I get up upset every day, but it is much harder to meet somebody because you know what at the end of the track. But having said that, I have many friends without MS who are single. It doesn't have to do with the MS. So yeah, that would be the biggest thing, but I am happy enough with my life to be honest. It is not the worst thing that has happened to me, well, it probably is, but life goes on.

In spite of her struggles with the illness, in general Anna is content with her life. This is because on the one hand she received much social support from her social network, but also because her priorities have not been compromised by her illness:

The things that are important to you remain kind of constant, then okay, it's a huge change that is happening in your life and it's a huge adaptation, but the essential bit of how you see yourself doesn't really change. I suppose I am what I am. I know who I am. I had good parents. I am comfortable with who I am. That's sound too Oprah'ish [...] Okay, I could change my job, but I like my life. I have been quite happy. So yeah, physically I can't do what I did before, and that's for real, that's real pain. But I never judged myself on physical things, I judged myself on my studies, friends and family. Those are the things that are important to me. I never judged myself by those other things.

Anna asserts that the situation would have been a strikingly different one if she had been a top-athlete or had children, but as she can continue to do the things that are important to her, and go about her daily chores as it were, she enjoys her life. As with Sarah, Anna searched for new hobbies that she can enjoy in spite of her physical restrictions. Her narrative details a balance of positive and negative aspects, where the illness experience has sooner been positive, this, demonstrating that people with a chronic illness have both “good” and “bad” days (Charmaz 1991) and that illness is something accompanying life, neither as something exclusively negative nor exclusively positive.

Jan is fifty-seven years old and was diagnosed with the primary progressive form of MS in 1994. He lives in the Netherlands, can only walk small distances, and uses a wheelchair or scooter to move outside the house. His illness progresses rapidly and he perceives weekly changes: “If my brother or sister haven’t seen me for two weeks, they are shocked because they see how fast the illness progresses”. Approximately eight years ago he met his wife Annemarie via a dating site. Although the illness influences their relationship, they try not to allow the illness overshadow the marriage:

We are both not very demanding. We enjoy the contact with our neighbors and their children. We are both very easy in our lives. If we want to go out, but the dishes are not done yet, we just leave them. To go somewhere is already exhausting, if we do the dishes we are even more exhausted, so we just do them tomorrow. It’s just a matter of priorities.

On occasion, Jan has the impression that he demands too much of his wife, but Annemarie expresses that she is happy to take over home tasks, such as doing the dishes, so as for Jan to invest his into the things they enjoy:

Annemarie: Our relationship just feels good. We enjoy everything that we can still do and furthermore we just try to make the best out of it. The situation won’t change, so it is important how you deal with it. It’s no use to hang your head; you have to make the best out of it. We just enjoy each other. At the end of the day we sit in our kitchen with the radio or TV and then we just talk. And that are our moments.

Jan: I’m not sure whether I dare to say this, but I find myself too much of a nice guy in order not to deal in the best possible way with my condition, and I think that ‘mevrouw’ [my wife] is too nice to not deal with it in the best possible way. I mean she does not deserve it that I am grumpy all the time. And of course sometimes I am grumpy or we are sad when my condition gets worse, but that never becomes too big of an issue.

Annemarie: Sometimes people say ‘how can you two stay so positive?’. This surprises people, but his condition also brings us closer together.

Jan: If our neighbor says that we are such a strange happy couple, I think that’s not what we do it for, but it is nice to see and feel that people not focus on your illness, but on who you are as a person.

Jan and Annemarie come across as a good team that has found a good way to address difficulties. They do not allow the illness to impinge upon their lives and they are grateful for the things that they can do together. Sooner than complaining, they enjoy the small moments together.

Happy through and by illness

Emily is fifty-two years old, divorced, and has three grown up children. Her first symptoms presented themselves almost thirty years ago, but she was officially diagnosed in 1988. She uses a walking frame at her

workplace and in her family home in Dublin. A wheelchair is used 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 as mostly positive:

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. 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 was very busy. 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.

Emily has a good social network and is in a happy relationship. Her friends are very supportive and helped her raise money to renovate her house so that she would have all necessary facilities downstairs. She says that people are extremely helpful and that she can rely on the assistance not only of her neighbors and family but also on passers-by on the street. She states: "I live every day. I have everything I need. Socially I do a lot, more than my friends maybe. I enjoy life".

Emily expresses that it is not at all fortunate she has Multiple Sclerosis, but rather that 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 a 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.

When I ask Alex, whether he thinks that there was a reason why he became sick, he replied the following:

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. 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. 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.

Alex is in his mid-fifties, married, has two sons and lives in the Dublin Bay. For twenty-seven years he was a chef, but when his first symptoms appeared approximately six years ago, his life changed completely. He suffers mostly from fatigue, and during the night, from muscle spasms:

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 going 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.

In spite of these big changes Alex comes across as a positive person. In the first minutes of our conversation he expresses: “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. Yet Alex’s biggest change has been his outlook on life. Before Alex was struck with Multiple Sclerosis he worked eighty hours a week; now he works at a learning center for people with disabilities. This, is the source of great satisfaction. He states: “My life is good and I am enjoying it”. Alex is not in denial of his condition, but tries to limit the impact of the illness on his life.

Samuel, is another research participant, who to a certain degree has a similar background to Alex: he too lives in Dublin, is in his mid-forties, married, and a 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 work as finance director in a stock company, which was a difficult step for he had invested many years of his life building up a career. He emphasizes, however, that he is now able to spend more time with his family and has consequently built a better relationship with them:

I had to search for 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. Samuel told me that he had been living his life from a negative perspective. Life for him had been rendered nothing more than a battle in which every morning he had to get up and fight. Samuel had been striving for perfection and thereby procrastinating through not reaching this ideal. While pretending to the outside world that he led a happy life, he was depressed and did not feel worthy as an individual. As in the case of Alex, the positive changes his diagnosis brought overshadow, at least for the moment, the difficulties caused by his illness. 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 concerned, less stressed, and has fewer worries.

We have thus seen two kinds of narratives. One the one hand our research has presented people who confirm that living with a chronic illness is difficult but who also signal that adapting well lessens the impact on happiness. On the other hand there are those who see their illness as an awakening blessing, which has heralded a change in the perception of life. Although both kinds of narratives demonstrate that disability and happiness are not mutually exclusive, the relationship between happiness and illness is different. In the first instance, people try not to let the experiences with the illness impinge upon their happiness while in the second, people actively use the illness as a source and vehicle for happiness.

IV. Discussion

The disability paradox

Such examples demonstrate that disability and happiness can coexist. While some people experience happiness *in spite of* illness, others experience it *through* the illness. This is supported in interviews other scholars have conducted with chronically ill people, where, “these experiences indicate that some of the outcomes of physical

impairment may be healthy and positive, that happiness may not only survive but increase following events such as spinal cord or traumatic brain injuries or cerebral palsy” (Meyers, 2000: 346). Freedman (1987) cites the case of a woman with kidney disease who says: “naturally, it makes many things in life very hard and interferes with lots of activities. Suffice it to say that I'm quite pleased with my ability to cope with this health problem and lead a worthwhile and happy life in spite of it or perhaps because of it” (Freedman, 1978: 122; in Albrecht & Devlieger, 1999: 979). Albrecht and Devlieger (1999) also speculate that the high quality of life is the result of a so-called ‘secondary gain’, which can often take the form of a re-evaluation of life and a change in priorities.

Though observing the different empirical examples, the disability paradox is confirmed, as people with a chronic illness indeed experience happiness and are content with their lives. However, we will see that the notions of the disability paradox can be deconstructed, firstly through a discussion of different interpretations and explanations of the disability paradox and then by critiquing the assumption upon which the paradox rests.

Albrecht and Devlieger (1999) confirm that, “a disability paradox exists”. The study of Ubel et al. (2005) further attests that people with a disability reporting a high quality of life is indeed paradoxical where, “people experiencing a wide range of illnesses and disabilities often report *paradoxically* high levels of QoL and mood” (my emphasis). Further: “many people are *understandably* sceptical that such self-reports are accurate” (Ubel et al., 2005) (my emphasis).

One interpretation Ubel et al. offer for the fact that people with disability report a high quality of life is that such self-reports are biased. To value test their hypothesis, the researchers (Ubel et al. 2005) analyze how reports depend upon the reference group interviewees have in mind. Therefore, do people report a higher quality of life in relation to the ‘normal’ population or in relation to people who suffer from a similar condition? The answer Ubel et al. provide is that although people reported a higher life satisfaction when they compared themselves to other people with a disability, in general their life satisfaction is similar to that of the general population. Yet what was precisely discovered, is that the self-reports of people with disabilities are largely accurate, rather than biased (Ubel et al., 2005).

To find an alternative explanation for the disability paradox scholars have shifted the focus from people with disabilities to the general population. One finding is that healthy people misjudge the effect of chronic illness or disability and ‘healthy’ people overestimate the impact of chronic illness or disability (Dunn & Brody, 2008). An explanation for this phenomenon is that when people imagine what life with a chronic illness or disability would be like, they tend to focus, narrowly so, on the most obvious differences, neglecting the full spectrum of other aspects unaffected by the condition. Moreover, the fact that people adapt to changing circumstances is also overlooked. Thus healthy people tend to arrive at rather pessimistic predictions about chronic illness and disability, further enforcing the disability paradox (Ubel et al., 2005).

What appears to be the general negative perspective of healthy people not only derives from a misprediction which is the result of psychological phenomena such as ‘focusing illusion’ or ‘underestimation of adaptation’ (Ubel et al., 2005), but also the widespread perception of society shapes how ‘healthy’ people view disabled people: “the political and discursive segregation of people with disability into a negative axis of evaluation inadvertently reproduces popular misconceptions that a life lived by someone with a disability is a bad, sad or inferior life” (Sunderland, Catalano, & Kendall, 2009: 711). Meyers (2000) points out that healthy people mostly get their ideas of living with a disability from conversations with people who have “little or no experience of life with disabling conditions”. The film industry is not immune to misrepresentation: “while movies entertain, they simultaneously provide viewers with information about disabilities, and, through the filmmaker's lens, they project representations of how individuals fit into a nation's social and political landscape” (Safran, 2001: 223; in Black & Pretes, 2007: 66). When people with disabilities are portrayed in a negative and stereotypical way, or indeed as *we*

would normally expect them to be, this shapes not only how the general society sees people with a disability, but also how people with disabilities view themselves (Black & Pretes, 2007). Likewise, imagining how we would fare in or under a certain condition or how we would fare if our children were to live with a condition is an alternative way of thinking about disability (Meyers, 2000). In summary, approaching disability through such mediated, generalized and representational optics, are always in our own 'ableist terms' (Imrie, 1996; in Meyers, 2000: 345).

While there are those who seek to explain the disability paradox, others sooner criticize its assumptions: "it is rare that any single attribute independently defines life quality. Life is more complex than that" (Koch, 2000: 758). Thus, health or illness is only one aspect of one's quality of life spectrum. Family relations; work satisfaction; education; marital status, etc also play a constitutive role (Koch, 2000) and by assuming that health is the only predominating criteria influencing quality of life, the developers of the disability paradox overvalue the importance of health whilst ignoring the fuller spectrum of existential and social factors.

There is the assumption that disability by definition leads to a low quality of life (Koch, 2000). Is it so pertinently unthinkable that people with a disability *can* and *are* happy? The life of every individual is patterned by both good and bad periods, and happiness is never promised, but qualified through certain causes and conditions, at times subjectively so, according to the individual's life disposition. Happiness is a relative concept.

The disability paradox carries serious implications and consequences not merely for people with a disability, but also for the tendencies and direction of scholarly research where such a paradox "impose[s] a range of limiting assumptions upon the reader, the writer and his or her resulting research" (Koch, 2000: 758).

Yet the author of this present work is not immune from the inclination to reproduce this perspective. By entitling the subheading *happy in spite of illness* and by using certain sentence constructs, an unexpectedness towards the experience of happiness in those with illness, is communicated. Discourse management only reveals more problematic social constructions within the consciousness of the writer such as 'she can *only* move around in the electric wheelchair', '*although* Sarah depends on eight careers, she *still* plans her life independently', '*in spite of* her restrictions, she comes across as a happy person', etc. Moreover, in looking back at the interviews, which were on illness experiences, a nuanced bias is apparent towards the negative consequences of being chronically ill. Thus in critiquing the disability paradox, automatically there is the danger of reproducing its very assumptions. Thus is demonstrated how strongly the view on happiness and disability, or rather, how the particular codifications of this relation, have been internalized.

Imperative happiness

The question of happiness and chronic illness has thus far been approached from the perspective of the individual and of society. But one can also place the experiences and attitudes of people in a broader context. If we look at the Greek notion of happiness, we see that it was ethically constructed where "to lead a good life, one had to cultivate and to exercise virtues, including personal growth, autonomy, and self-acceptance" (Dunn & Brody, 2008: 414). From this it follows that happiness is a universal, normative concept. Yet one could argue that happiness is not an individual experience but something, which is given shape by the social sphere. Indeed, in our current society, the pursuit of happiness is seemingly an important virtue: Nozick (1989: 117) points out how naturally and unobstructedly we [can] think it (happiness) the most important thing in life: "in fact, one might accuse modern-day Westerners to be obsessed with happiness, considering the ever-growing number of psychological and popular-science books examining happiness and how people can increase it" (Mauss et al., 2011: 813).

People are encouraged to seek a happy life and search for 'help' if they are not able to accomplish this alone. Herein they are supported by the State that facilitates the pursuit of happiness by offering psychotherapies, which create a normality where people have to realize their potential and pursue happiness (Rose, 1999). People

have strongly internalized this notion, one, reflected in the narratives of people with MS. With Jan, for instance, we see how he opposes sullenness or unhappiness by favoring *being happy*. Interestingly, the main reason for wanting to be happy is his wife and the people around him, this, demonstrating that happiness for some is not important as an individual experience, but is constitutively qualified in relation to others, collectively.

Looking at the disability paradox from yet another perspective, it can be argued that people with a disability or chronic illness want to participate in the general trend of pursuing happiness. Happiness it seems, can be retrieved from suffering: “Several person with disabilities [...] pointed out that it was precisely the experience of a serious illness that changed their life purpose as well as their value system” (Marinic & Briljacic, 2008: 530). In line with Nozick (1989) one could ask as to whether the experience of suffering is necessary to experience a profound form of happiness. Nozick (1989) further points out that we have to be careful not to take happiness as the most important goal in life for it can prove self-defeating, this carrying the risk of disappointment should such a goal not be achieved (Mauss et al., 2011).

V. Conclusion

This study has sought to question the assumptions underlying the disability paradox and demonstrate that such a paradox represents non-disabled people’s judgment of the quality of life of people with a disability. The paradox is essentially problematic not only because it ignores the perspective of people with a disability themselves, but also because people living with a chronic illness or disability are seen as having a low quality of life. Using empirical examples of people who have been diagnosed with MS this study has argued that happiness and disability are not mutually exclusive phenomena, but coexistent states of being where people can indeed experience happiness *in spite of illness, or through illness*.

Furthermore, through self-reflection, the author has sought to evidence how persistent and persuasive the disability paradox is. Despite the author having stated that people with a disability or chronic illness experience happiness, a subtlety conscious doubt is present, questioning whether this happiness is of the same quality as the happiness ‘healthy’ people experience. More research that explicitly addresses this question could provide promising new insights.

Although this study has described chronically ill people who experience happiness, living with a chronic illness or disability is by no means easy and adaptation is neither quick nor uniform. The study, rather, has sought to reveal that people who are sick or disabled are not necessarily unhappy, as is commonly believed and perceived. The fact that a good quality of life and happiness is experienced also does not imply that frustration, sadness, lament and desperation are not present within the existential spectrum of the individual. Living with a physical impairment likewise can imply a life –characterized by pain, frustration, humiliation, restricted opportunity, and considerable extra cost–, but “we must put these experiences in the context of joy, satisfaction, and happiness that can and usually do characterize lives of people with physical impairment” (Meyers, 2000: 345). Chronic illness should be analyzed as a multifaceted experience (Thorne & Patersson, 1998) and as always, idealizations of such contexts and persons are the pitfalls to be avoided yet easily encountered.

The experience of illness and the perception of happiness is variable and subjective, rooted in *biography* and *difference* where, “it is inappropriate to make generalizations or assumptions regarding the happiness, sadness, challenges or joys of people with disabilities as a sweeping category” (Sunderland, Catalano, & Kendall, 2009: 713).

The title of the present study raises the question of as to whether chronic illness as a source of happiness is a paradox or perfectly normal – it can be both. It has become clear, through this study, that people with a disability experience happiness and can have a good or excellent (note the temptation to write *even* excellent) quality of life,

the mystery remains for most as to *how* and *why* this is at all possible. In conclusion, where the positive is hard to imagine, the context requires us to be more imaginative.

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