Research article

**Disabled people and subjugated knowledges: new understandings and strategies developed by people living with chronic conditions**

**Abstract**

This article provides a contribution to our understanding of the knowledges and strategies developed by people living with chronic illnesses, based on an empirical study done with this population in England and Portugal. It begins by mapping out the debates in disability studies which have focused on embodiment. It continues by arguing that disabled people constantly have to negotiate codes about the body based on normative notions of the body, which I termed normative corporality. The main themes arising from participants’ accounts are then identified and discussed. The article ends by arguing that the knowledges and strategies developed by disabled people are often not noticed or are devalued as we tend to value knowledges of the body that come from established systems of knowledge, or from bodies our society deem normative. Thus, disabled people’s knowledges can be conceptualized as subjugated knowledges.

**Keywords**: chronic illness; embodied knowledge; subjugated knowledges; strategies.

**Introduction**

Over the years, Disability Studies has paid much needed attention to mapping out and describing disabled people’s societal experiences of disablism and locating the ‘problem’ of disability in society. In this article, I argue that this important work can also be complemented by understanding and describing the many ways in which disabled people develop expert strategies and knowledges which I refer to as subjugated knowledges (Foucault and Gordon [1972] 1980). These are not always recognized or identified by others as being important. Being able to identify and describe these types of knowledges is essential for disabled people because they are often perceived by society as being dependent, needy, etc. However, in order to navigate a world that is not made for their bodyminds (Price 2011), a world that offers mostly barriers and lack of understanding, disabled people need to develop expert strategies.

On the other hand, even though some strands in disability studies have not always wanted to look at the lived reality of the body, often with good reason, since this can deter from focusing on the real barriers that need to be tackled, I would argue that as a discipline, disability studies is now mature enough to be willing to understand that disabled people’s embodied experience is a rich and complex one. Focusing on the knowledges disabled people might develop through their bodyminds does not mean we stop acknowledging social barriers, but rather, that we are willing to look at the full complexity of a person’s lived reality. Furthermore, it means that we understand that disabled people are not just bodies facing barriers but they are, rather, expert bodyminds developing intricate strategies that allows them to address a disabling world. I am using Margaret Price’s concept of bodymind here to indicate I am unhappy with the cartesian split of body and mind and to recognize that the mind and the body affect each other in ways that it is important to recognize (Price 2015).

The main argument I will develop in this article is related to thinking about the role of impairment, illness and what we could call the body-felt as contributing knowledge and significance to the human experience. By body-felt I mean the carnal and material existence of real bodies and their subjective experiences of embodiment. At the same time, I want to investigate the cultural contexts that frame the worldly presence of bodies, namely through the codes of ableism. This concept of ableism (Campbell 2009) refers to the larger framework that governs our society’s understanding of ability and disability – this includes the often untold norms and codes that shape our understanding of bodyminds (Price 2011) and our notions of disability. In this regard then, it is more equivalent to terms such as patriarchy and whiteness (Mallet and Runswick-Cole 2014) as it allows us to focus on the systems of beliefs and values that underpin our understandings of ability and disability and that allow for disablism to occur in the first place. I also intend this to be a contribution to what has previously been described as cripistemologies – the uncovering and acknowledging of crip-specific knowledge (Johnson and McRuer 2014).

**Framing the debate: impairment and the body**

Bodies don’t exist in a vacuum. They are, of course, immersed in cultural practices shaped through language. In addition, the lived experiences of bodies have often been shaped by systems of influence, namely patriarchy (which impacts our understandings of gender roles and expectations) (hooks 2000b, 2000a; Beauvoir, Borde, and Malovany-Chevallier 2010), heteronormativity (which impacts our understandings of sexuality and gender expression) (Warner 1991; Rich 1980), whiteness (which impacts our normative understandings of race and ethnicity) (Ahmed 2007, 2012) and ableism (which impacts our understandings of ability and disability) (Campbell 2009; Goodley 2014). All of these will often prescribe an extremely narrow recipe of what bodies should be and how they should behave. Whilst these are frameworks that affect how people think of their bodies, people also actively negotiate these aspects everyday of their lives. They make informed decisions and some of them might actively carve their own paths facing the consequences of these choices. For instance, people who decide to challenge established gender norms in a visible way may have to pay particular societal consequences for this (Harrison, Grant, and Herman 2012; Butler 2006).

Thus, bodies exist in this tension between their own individual carnal experience and societal and cultural rules which shape how they are perceived and, often, what they are told they can or cannot do. I argue that we must pay close attention to both aspects of this constellation. For example, whilst in some Western countries it has been deemed acceptable for a gay or lesbian person to form a family with a person of the same sex, in many places in the world this idea is still seen as unacceptable in terms of what these bodies should be allowed to do or how they should operate in the world. Equally, disabled bodies have been designated as such by a set of cultural practices (industrialization and capitalism) (Oliver 1990; Slorach 2016) and beliefs (ableism) (Campbell 2009; Goodley 2014) that have deemed some bodies and abilities to be inferior to others and, as a consequence, have dislodged them from societal participation and contribution. As a consequence, some of these bodies’ abilities (using wheels instead of walking, signing instead of talking) have been constructed as inferior or their access needs have simply been ignored (such as by architecture) and not considered an equally acceptable way to do things. Because these bodies have been constructed as inferior and lacking, the ways disabled people have related to their bodies have historically been seen as of little significance when compared to what has been constructed as the ‘normative’ way to do something. Our society tends to place such a focus on walking, for instance, that wheeling around instead, and the strategies employed to do this, is often considered second-rate.

It should also be added that in the context of disability studies the initial Marxist and materialist tradition (primarily in Britain) naturally focused its efforts on what mattered most: addressing disability as a social barriers phenomenon. This work is still really only beginning, particularly in peripheral or developing countries and it is important that this work continues to be addressed.

The aim of this article though is to shed a different light on issues of embodiment and impairment in a way that does not reiterate the disenfranchising arguments existent before the influence of disability studies. Many disabled people’s views about impairment and embodiment have often been side-lined because, crucially, they were either locked away in institutions (in rich countries) or living the most pauper of lives without access to resources in poorer countries. In either case they were experiencing an insurmountable summit of social barriers that did not allow them access to education and to public life in general and that made living with impairment a hard experience indeed.

The authority voice on the experience of impairment was firmly given to biomedicine and its allies. As Liz Crow points out, ‘Our fears about acknowledging the implications of impairment are quite justified. Dominant perceptions of impairment as personal tragedy are regularly used to undermine the work of the disabled people’s movement and they rarely coincide with disabled people’s understandings of their circumstances.’ (Crow 1996, 211).

Whilst the focus on social barriers must remain at the crux of disability rights and disability studies, feminists in disability studies have argued from the beginning that there should equally be a place for exploring the body and impairment in a different fashion from what had been the previous focus (Morris 1996, 1991, 1989; Crow 1996; Thomas 2007, 1999; Wendell 1996; Corker and French 1999). As Jenny Morris also argued early on, ‘we can insist that society disables us by its prejudice and by its failure to meet the needs created by disability, but to deny the personal experience of disability is, in the end, to collude in our oppression.’ (Morris 1991, 172). As Wendell also mentions, ‘when people are systematically disadvantaged in a society, their thoughts, feelings, intuitions, and perceptions are systematically ignored or undervalued, and they themselves are taught and continually pressured to undervalue them in relation to those more privileged people.’ (Wendell 2008, 214). In other words, thoughts and feelings matter because systems of domination certainly can influence how people feel about themselves consequently, paying attention to them is in itself a political act.

It was perhaps Liz Crow who best articulated the need to have a fresh and political look of impairment in what is now a classical essay in feminist disability studies. She stated that the subjective experience of impairment is as important to acknowledge as external barriers. She reminded us that understanding impairment only as personal tragedy is not inevitable and as disabled people, we don’t need to accept non-disabled people’s understandings of our bodies (Crow 1996, 210, 211). Carol Thomas later summarized this argument by offering the idea that it should be possible to understand the body as being ‘*bio-social* in character’ (Thomas 2007, 135 – author’s emphasis).

This is a key argument in thinking about the role of the body for disabled people. It is in a sense a political project on its own because it is about arguing that disabled people have the right to explore their own meanings of embodiment and these do not have to be the same as the non-disabled world’s interpretation of impairment. Furthermore, because impairment is bio-social in nature, this means we can’t address it without addressing the social, political and cultural structures that surround disability.

Although debates concerning the role of the body and impairment as a political project were brought forth primarily by feminists within disability studies, it is important to mention that they were also developed by some sociologists allied with disability studies who were coming from a phenomenological background (Hughes 2002; Hughes and Paterson 1997; Paterson and Hughes 1999), and articulated also by poststructuralists in disability studies who criticized the impairment and disability divide proposed by the social model of disability (Corker and French 1999; Corker and Shakespeare 2002; Shildrick 1997). Many North American disability studies scholars who were coming from a cultural studies background also had more diverse positions regarding the role of the body which expanded the debate (McRuer 2006; Siebers 2006, 2008). All of these contributions advanced thinking regarding the role of the body and impairment within disability studies.

At the same time, disability arts and culture helped explore different notions of the impaired body (Kuppers 2011; Masefield 2006) and present these to an increasingly higher number of audiences. As Bill Hughes puts it, ‘in practice, disabled people began to take pride in their lives and their bodies’ (Hughes 2014, 114). Hughes also argues that in the last twenty years these new ideas about impairment have been integrated in disability studies and have helped shape recent ideas in the social model itself (Hughes 2014, 115).

**Normative corporality**

Susan Wendell argues that the dismissal of disabled people’s knowledges about impairment and the body is serious because it constitutes ‘knowledge lost’ which is in fact not shared with others to aid them on a similar journey (Wendell 1996, 109). Because Western culture creates both idealized notions of the body and believes that the body is something we can control in its entirety, knowledges of the impaired body do not circulate and are not shared. This has particular consequences for our culture, since most people are often ill-equipped to deal with illness and disability and the silence around these topics only increases our fear and misunderstanding of these topic (Wendell 1996, 109). In addition, some of these knowledges have been side-lined or not valued because they constitute a non-normative way to approach issues of embodiment – and this is an important point.

The decade-long enforcement of right-hand writing for left-handed children, forcing children to speak orally and lip read, forcing people to wear prosthesis that don’t work for them, are all examples of how far we have been willing to police non-normative bodily practices for the sake of standardization and creating a faux sense of normative corporality.

The concept of *normative corporality* which I am proposing here refers to the artificial and cultural construction of rules relating to how corporality should be and how it should behave within an ableist system that privileges some bodies and abilities over others. Crucially, the concept calls our attention to how privileging only some kinds of bodies means that the knowledges and contributions of those bodies and abilities that are considered inferior and lacking are *discarded and wasted*. Again, this is something that has affected bodies which simply do not conform be it in terms of ability, gender or sexuality. If one moves through the world using wheels or a cane for navigation, one builds a set of knowledges which are different from those accumulated by people who walk. Walking people who are visual might need visual cues to get somewhere whilst visually impaired people might be able to navigate the environment using a cane, based on a mental map built from experience or they might use a technique called echolocation. This has recently been identified on a number of visually impaired people (i.e. scientific knowledge has proved that it exists) and it consists of a sonar-like technique which helps visually impaired people navigate the world using echoes from repeated tongue-clicks (Kremer 2012; Tresniowski 2006). A scientific study with visually impaired people who use this technique concluded that individuals can use echolocation in a way that can be considered similar to vision (Thaler, Arnott, and Goodale 2011, 8, 10).

Despite these and other techniques being used for navigating, as a society we tend to prioritize one knowledge (in this case visual cues) over the other, in the process also implying that one is better or more desirable than the other. Not just better but the ‘right way’ to do it. Thus, we build notions of what corporality *should be* whilst policing those who do differently. The point is that such notions affect *everyone*, not just disabled people.

**Methodology**

This article is based on empirical work conducted with people living with chronic illnesses in England and Portugal. The research sought to find out the daily experiences of people living with the following fluctuating and/or unpredictable conditions: Fibromyalgia (FM), Myalgic Encephalomyelitis (ME), Chronic Fatigue Syndrome (CFS) and Multiple Sclerosis (MS). One of the research questions focused on finding out what knowledges and strategies people with these conditions developed in their daily lives and this article focuses on this aspect of the research.

This research solicited first-person accounts from participants living in England and Portugal. Narrative methods were used, in particular the narrative correspondence qualitative research method (Grinyer 2002; Milligan 2005; Thomas 1999) – based on inviting and analysing the written or oral accounts submitted by a sample of people living with chronic illnesses in both countries. Participants were invited to submit their written or oral accounts through an online form available on two websites (one in English and one in Portuguese). After receiving participants’ accounts, they were asked further questions via email, which allow them to elaborate further or clarify aspects of what they had said. This conversation often added important details to what participants had first offered and allow for a more in-depth understanding of issues being raised.

This method was chosen because of its potential to allow possible participants to write or orally record their accounts in a digital file on their own time. Many people with fluctuating chronic conditions find it hard to schedule things ahead of time as they do not know how they might be feeling at a certain time. Equally, sitting in for an interview may not always be the best situation for someone who experiences a lot of pain and fatigue.

A research information sheet was circulated through patient associations and online groups as well as through internet forums and websites in both countries, soliciting the personal accounts of people older than 16 years old, who self-reported as having been diagnosed with Fibromyalgia (FM), Chronic Fatigue Syndrome (CFS), Myalgic Encephalomyelitis (ME) and Multiple Sclerosis (MS) and who lived either in England or Portugal or both. I mentioned that I was interested in finding out more about their daily experiences with living with a chronic illness and listed a number of possible topics that people could refer to if they wanted as well as stating that participants were welcome to tell me about any aspects of their lives that they wished to share.

In terms of data analysis, I used thematic analysis to organize accounts in to themes and I then defined subthemes. This article is based on one of the main themes identified in the data. I then used narrative analysis to approach the accounts in detail. Narrative analysis (Andrews, Squire, and Tamboukou 2008; Squire, Andrews, and Tamboukou 2008) includes several different types of approaches but crucially it is more concerned with looking at the context of a person’s account as an analytical unit, rather than bringing together several pieces of data in a fragmented way (Riessman 2008). For this reason, I present here only a few selected accounts from participants which are representative of the larger theme and sub-themes being discussed but I use large extracts of these participants’ narratives (although I do edit them for space and content value). Doing so allows for the voices of research participants to be present instead of being filtered only by the words of the researcher. The role of stories and personal narratives when it comes to disability remains essential in particular in countries such as Portugal where such stories have not really been as visible as in other countries.

Certainly, as Tanya Titchkosky and Rod Michalko argue, ‘To say anything about disability is to *tell* something of the life of disability – its meaning – and “to tell” is the Latin root-meaning of “narrative”. Disability, then, always has a narrative form; insofar as we say, do, or imagine something about disability, it is a storied life.’ (Titchkosky and Michalko 2014, 101 – authors' emphasis). As Arthur Frank also contends, when the ill-body articulates a story it is a personal task but one that has a social aspect to it (Frank 1995, 2). Therefore, personal narratives focus on the lived experience of a person but they do point to a wider context that shapes that person’s life.

At the end of each extract, I identify participants by using a pseudonym (since I asked participants to choose their own name) age range, illness(es) and country. This helps provide context about the narrative and background of participant without disclosing too much about the participants as the narratives can sometimes include quite a lot of detail already and it is important to preserve the anonymity of the participants by not including too much background information.

**Findings and Analysis**

Three main themes were found when analysing the data pertaining to knowledges and strategies developed by participants. These are explored in detail below, along with illustrative extracts from participants’ accounts. Although the research demonstrated differences between Portugal and England in other aspects, such as access to benefits and state support as well as support in employment, there were a lot of similarities in themes arising in both countries that focused on knowledges and strategies developed by participants. I received accounts from both genders but I chose extracts that were most illustrative of the themes identified here and these happened to be all from women.

***Taking responsibility for their lives and wellbeing***

One of the most important themes found is that participants indicate taking a lot of responsibility for their lives and for establishing a good standard of self-care in their lives. Despite the fact that they are often fighting difficult impairment effects (Thomas 2007), such as chronic pain or extreme fatigue, they continue to try to see what they can do to make their lives better and seek new solutions for any issues that they are faced with.

This aspect is well illustrated by Cathy’s insight, a British woman in her 40s, who had been diagnosed with M.E. and C.F.S. Even though she mentioned that there were many aspects of her life that were challenging, she also wrote about always finding new ways and believing in her ability to keep moving forward.

ME has taught me that I'm incredibly strong and that feelings (emotional, physical etc) are not the most important things in life. There's a well of resources deep within me that keep me going, though I have been suicidal at times. I mainly keep on top of it by thinking positive thoughts. … I will not give up trying to get well and I'm sure that I will one day. Meanwhile I stay optimistic most of the time. (Cathy, F, En, 41-50, ME, CFS)

Despite the admission of very difficult times, illustrated here by her mention of suicidal ideation, she also discusses how she has learned that the way she feels, either physically or emotionally, is not necessarily the main thing to focus on or the most important thing in life for her. This seems to provide a recognition for her that there are a variety of different aspects to life and that for her it is possible to enjoy life with impairment limitations and pain or that it is possible to value other aspects of her life. Her discussion regarding the vast number of resources she always finds within her, which allow her to continue, is also relevant to notice. This really illustrates well the immense strength demonstrated by many participants in the study. It also demonstrates an ability to find ways to keep going, despite difficult physical and emotional situations.

A similar sense of purpose and drive was present in other narratives received. For instance, Luisa, a Portuguese woman, wished to detail in her narrative how she was able to leave behind what she described as an emotionally abusive relationship and was able to begin a new life.

[That summer] during our holidays my husband and his family insulted me so much that I decided to put a stop to this hell. I thought: if I am with someone but feel alone, rejected and misunderstood, then it is better to be alone. So [shortly after], I left the house and looked at life and at my illness with new eyes. I told myself ‘you can do it’. . . . After this I faced many difficult years, things got worse at my job but my inner strength got better and better. ‘I can do this’, I thought. The more pain and limitations I experienced the more positive thinking I had to do. (Luisa, F, PT, 41-50, FM)

Luisa shared how it took immense strength to leave behind a relationship where she reported feeling often misunderstood by her husband but also insulted and humiliated. She did this at a time when she was not very well and she had to consider the fact that she had a small child to take care of and provide for. She herself acknowledged in her account that she was not sure whether she would be able to make such a drastic life transition by herself, support herself and her child but, in the end, she seems to have been able to find a new path.

Other participants focused their accounts on their ability to value the days when they felt better and their ability to listen more to their bodies. This is illustrated here by Susan’s words, a British woman in her 50s:

Need to try and value the better days and try not to over stretch myself. ME helps you value the basic things in life, learn what your body is trying to tell you. Be grateful for those who understand your condition and try and educate those who don't. (Susan, F, EN, 51-60, ME)

This ability to be able to listen to their bodies and in general be more in tune with their bodyminds was stressed by many participants as a fundamental aspect that allows them to drive forward the changes they tried to implement. This is a key strategy developed by participants that allowed them to gain a new re-engagement with their bodies and lives. This process is absolutely necessary in order to re-orient the experience of illness – from one which is mostly only negative to one where people find small things to value and cherish.

Many participants also reported having days where they were unable to bathe, wash their hair or eat properly. This kind of impairment effect would, naturally, have a severe impact on anyone. I argue that it is therefore important to recognize the efforts that participants report in terms of trying to find a silver lining, despite the severe effects of the illnesses.

***Developing and enacting strategies***

A second significant theme is that participants described enacting a number of important strategies that might not always be visible or recognized by others. These strategies are diverse and range from very simple actions, such as adjusting and changing the furniture in a room in order to make life easier, to very complex ones, such as changing their whole diet and outlook on life. Participants reported developing these strategies in connection to several aspects of their lives, from aspects that pertain to their personal and home life to aspects that focused on how they managed their jobs and work environment.

Many participants reported consciously saving energy by not bathing or showering very often, as exemplified here by Cathy:

I don't wash or shower very often because it uses up so much energy. I only go out if it's absolutely necessary. It also uses up too much energy and I'm forced to breath in people's fragrances, which make me iller, even through a mask. . . . I do fairly well at looking after myself daily, though it's terribly difficult. I have to treat myself with kid gloves. My home's a mess because I don't have the energy to clean up and tidy all the time. I do a little when I can and as long as I focus on the most important job of preparing, cooking and eating healthy food I feel that I'm coping. Sometimes I can't do that. Throughout the winter I didn't stick to healthy eating and my health has gotten worse. I'm back on track now… (Cathy, F, En, 41-50, ME, CFS)

Although this speaks to the severe effects experienced by people who live with these illnesses, it also demonstrates that participants make conscious efforts around managing and spending their energy. In Cathy’s case, prioritizing food preparation becomes quite essential to her day and this is where she chooses to spend her energy because she understands food preparation and choices around this may have an impact on how she feels. This also means she decides not to spend as much energy cleaning and tidying up as this kind of activity means dispensing quite a lot of effort. Whilst most healthy people might consider bathing essential, for Cathy this is an activity she cannot take for granted. Thus, choices around energy consumption and saving demonstrate a sophisticated understanding of how to manage these types of conditions.

These aspects were very common in the narratives received and are further illustrated here by Teresa’s account, which also focused on the importance of managing her energy in her personal life so that she can have enough energy for her job:

I had to stop doing many things, I have reduced considerably my daily activities so that I can go to work every day. I don’t go out nor do I entertain people at night in my home because then I can’t sleep and the next day I feel extremely tired and my work day becomes torturous. Whenever I eat out it is very stressful because of the chairs, it is horrible and sometimes I have to ask to get another chair when this is possible. Sometimes I feel like an ‘ET’. (Teresa, F, PT, 31-40, FM)

This extract of Teresa’s account provides interesting insight into how energy must be carefully managed and directed to the most important tasks. In this case, energy is managed by anticipation. Teresa knows she won’t be able to entertain people and then go to work the next day, without consequences, therefore she avoids this situation and her energy is directed towards her job.

These are important aspects to note as they challenge current misconceptions about these illnesses – often participants have reported being seen as lazy by others. I argue here that by making conscious and informed choices around management of energy, participants are demonstrating a skilled ability to be in tune with their bodies and to make choices that favour their wellbeing. I also want to suggest further that these choices come as a result of careful consideration and planning as participants report having to choose carefully where their energy is spent.

For other participants, these kinds of strategies might also involve researching and trying out supplements and alternative therapies. For instance, Susan mentioned that:

I have found alternative medicine a lot more supportive eg. Osteopaths/Kinneologists who see you as a whole person and look to anyway to help rather than the presenting illness. I have found supplements more useful rather than some prescribed drugs, due to severe side effects. (Susan, F, EN, 51-60, ME)

Whilst it might be easy to dismiss accessing alternative therapies and taking supplements, again I argue that there are important aspects in doing this. Firstly, they really represent the lack of support from biomedicine, with almost all participants in this research reporting difficulties in their interactions with doctors. Secondly, they demonstrate that people are not simply standing by waiting for biomedicine to intervene and help. Participants become active in their search to enhance their wellbeing and this aspect must be appreciated as an active form of resistance to traditional systems of knowledge and as an active way to continue to seek wellbeing, despite obstacles and difficulties.

***Having to negotiate embodiment changes with others***

The third main theme identified in participants’ accounts is that any changes that participants may feel necessary to implement or need to enact, often have to be very carefully negotiated with others. Other people around them often continue to expect those bodyminds to operate in the same manner they did before. Participants report there is often little recognition that things have changed for them and that they need to adapt their lives to the new reality. This aspect is interesting to consider as our bodyminds have a collective existence as well as a personal one. We constantly negotiate our bodyminds with others. For people whose bodyminds are able to do a lot this can be perhaps less of an issue. On the other hand, for bodyminds whose capabilities have changed, shifted or who now suddenly need to negotiate barriers in the environment, this can be a challenge.

This aspect is illustrated here by Teresa’s account:

We used to travel [to our family house in the country side] which is 3 hours away and this became very complicated for me because I was expected to clean the house on arrival . . . and it became impossible for me to go there. But [my husband] doesn’t understand this, rather, he claims that he understands but refuses to accept the fact that I can no longer do these sorts of things. (Teresa, F, PT, 31-40, FM)

In this particular example, even though she has now been diagnosed with a chronic condition which manifests with widespread chronic pain and fatigue, she reports that her husband still expects her to clean their vacation house as in previous instances. There is also a gender aspect manifesting in terms of the expectation that she should be the one cleaning and making the house ready for the family – this was more predominant in Portuguese narratives. In addition, there is a lack of acknowledgement of her new circumstances, therefore, in a certain sense, her body is not just her own but she must negotiate it with the expectations that others around have of her body. Such expectations are often framed by all sorts of misconceptions about people who have chronic illnesses. Participants often report that others have real difficulty understanding how these illnesses affect them and how their bodyminds have changed, as Susan illustrates here:

Other peoples’ perception, they generally do not understand, they only see you having a meal or coffees say you look well. Don't realise you struggle to get out of bed, cook or if you didn't go out for coffee you would climb the walls at home. They do not see you lying in bed sometimes in a darkened room for hours on end. They do not know the isolation depression and mind hallucinations that you struggle with. (Susan, F, EN, 51-60, ME)

Susan’s points also offer an important insight into how negotiating her bodymind with others might bring with it all sorts of difficult interactions. She reports having experienced lack of understand from others, especially when she has been out for a coffee or a meal. It seems in these situations some people have assumed she is well and there is nothing much affecting her.

These aspects call our attention to how binary our culture’s understanding of illness and wellness can be. It is often easy to interpret how someone looks or the fact that they may be out and about as a sign of them being well. Our cultural signifiers for illness are often illnesses such as cancer which can often have visible effects and that are also perceived as cultural signifiers of character (Sontag 1991). But nowadays even such illnesses don’t necessarily mean that the person will physically present as *always* being poorly. Therefore, the assumption that illness or someone’s bodymind state should be immediately perceived from the outside is, I argue, part of the problematic cultural codes that sustain ableism. It is therefore of extreme importance that we begin to decode and analyse such codes because they are the heart of our understandings of normalcy and disability.

In this account, Susan highlights the difficulty of navigating a world that expects you to look ill or disabled if you claim to be so. A world that expects to be able to readily read you and draw conclusions about you. If you are out for coffee, then you must be well enough. However, as Susan mentions, this disregards the complexities of a person’s life. They may be out, but they may have also have had a horrible night or they may be out but be in pain. It is ableist, therefore, to assume that one can tell how a person is really feeling by simply looking at them or seeing what they are doing. The same could be argued in regard to other labels as well, such as mental health or autism.

I argue that knowledges and strategies developed through the body are never just a personal thing because, even though they might be developed by a particular body, they constantly have to be negotiated with others around. Thus, in the same way that impairment is ‘bio-social in character’ (Thomas 2007, 135), knowledges developed about the body are also bio-social because they are shaped and negotiated through cultural norms. Even if someone learns and decides to do something differently when compared to before, this is a process that often must be negotiated with others as those around may not be ready or willing to accept such changes.

**Conclusion: disabled people’s knowledges of the body as subjugated knowledges**

I argue that our understandings of the body are mostly influenced by our notions of normative corporality – the artificial and cultural construction of rules relating to how corporality should be and how it should behave. For instance, the fact that you should hold a painting brush with your hand and not your feet or mouth. We value mostly the knowledge of bodies which we read as normative. Yet, as the participants above demonstrate in regard to the experience of chronic illness, there is a wealth of knowledge and strategies people with chronic illnesses can develop, which demonstrate a sophisticated engagement with the body. Yet, such knowledges might be often unacknowledged, easily disregarded or not even noticed by others.

Furthermore, I would suggest that the difficulties in talking about illness and expressing the needs of the ill or impaired body arise from the policing practices ableism does of the knowledges of illness and impairment. Such practices are intimately allied with imperialist capitalist practices of which bodies count in relation to work and production (Oliver 1990; Goodley 2014). Western modernity has also imposed a number of binaries (health/illness, able/disabled) that entail hierarchies and shape particular patterns of thought. These don’t account for indeterminacies and most especially for any kind of vulnerability recognized in the human condition (Davis 2006). This points us in the direction of a hierarchy of knowledges – a topic which has been approached in particular detail by Foucault and by postcolonial thinkers (in slightly different forms).

In his lecture of January 7, 1976 Michel Foucault discusses the notion of subjugated knowledges as having two distinct meanings. First, he identifies what he sees as an epistemological shift taking place in the last few years at the time of his lecture. Thus he identifies subjugated knowledges as existing within erudite knowledges as ‘those blocs of historical knowledge which were present but disguised within the body of functionalist and systematising theory and which criticism—which obviously draws upon scholarship—has been able to reveal’ (Foucault and Gordon [1972] 1980, 82). Then he goes on to describe the other meaning of subjugated knowledge, which is of much more interest to the argument I want to explore next in this article. He defines these as ‘a whole set of knowledges that have been disqualified as inadequate to their task or insufficiently elaborated: naive knowledges, located low down on the hierarchy, beneath the required level of cognition or scientificity.’ (Foucault and Gordon [1972] 1980, 82) Within these he explicitly includes ‘even directly disqualified knowledges (such as that of the psychiatric patient, of the ill person, of the nurse, of the doctor—parallel and marginal as they are to the knowledge of medicine—that of the delinquent etc.)…’ (Foucault and Gordon [1972] 1980, 82). He further argues that it is through these and through their re-appearance that criticism can perform its work.

This is both a critique of the systematic systems of erudition that constitute academia (and its exclusions) but also a signal of the importance of ‘local popular knowledges’ in dislodging their primacy and exclusivity. For both senses above he is also clear that these subjugated knowledges have been ‘concerned with a *historical knowledge of struggles.* In the specialised areas of erudition as in the disqualified, popular knowledge there lay the memory of hostile encounters which even up to this day have been confined to the margins of knowledge.’ (Foucault and Gordon [1972] 1980, 83 – author’s emphasis). Thus we could suggest that lay knowledges about illness and the body have been disqualified and marginalized due to the predominance of specialist scientific knowledge on the subject as well as the focus on normative knowledges of the body.

We have therefore been unable to value and construct a solid body of knowledge related to the experience of illness, the body, impairment and disability as well as the interactions of these with the social world. Such knowledges have therefore been wasted – as sociologist Boaventura de Sousa Santos argues in relation to the effects of colonization in regards to knowledges of the South (2008, 1994). It could, therefore, be argued that what one may describe as the subjugated knowledges of disabled people have historically been subjected to a massive *epistemicide*, as Santos calls it (Santos 2007, 2008) – an erasure of valuable knowledge. Disabled people have effectively been discouraged to produce and pass on certain types of specific knowledges about our bodies and impairment that could be beneficial to others.

Thus, I argue that valued epistemologies of the body became exclusively those that pertain to normative corporality, those that refer to normative bodies and their expectations.

These are the epistemologies to which Western modernity ascribes value to, in this case, mostly those produced by science and biomedical discourse. This, in turn, has had tremendous consequences for disabled people everywhere because only knowledges constructed *within* the parameters of normalcy are in fact considered valid.

In the same vein of thought, I would argue that subjugated knowledges of people who experience illness or impairment certainly seem to be policed and de-valued by the codes of ableism and the codes that construct and enact normalcy. By policing here, I mean a mechanism that chastises or ridicules those who want to talk about such knowledges. This contributes to the process of constructing disabled people as ‘abnormal’, ‘undesirable’ and, worse, overall ‘non-existent’. The production of disabled people’s ‘non-existence’ could be argued to exist for instance in something as simple as inaccessible architecture. If all buildings tell a story, inaccessible buildings are constantly re-telling a certain narrative that renders disabled people as non-existent since they cater only for *some* kind of people. This, of course, extends to all other areas of the social sphere. Even when disabled people’s existence is acknowledged, it is often the case that we are constructed as either sub-human or simply victims that can only be ‘redeemed’ through the specialized knowledge of biomedicine. Yet, as I demonstrated here, participants in this study are extremely knowledgeable of their bodies and the limits of their bodies. They revealed intricate knowledge of their bodyminds and how to manage them. They develop a minutia of bodily knowledges and strategies that sustain them in their interaction with both illness and society. Participants, therefore, seem to benefit strongly from the knowledge they gain from their newly discovered bodies.

I propose that a new understanding of illness must come to the fore. One which understands illness not only as a kind of loss but also as a command of something. Something important: a person’s bodymind. This understanding is crucial when we compare it to the importance of established systems of knowledge, such as biomedicine, which ascribe little expertize to the person.

**References**

Ahmed, Sara. 2007. "A Phenomenology of Whiteness."  *Feminist Theory* 8 (2):149-68.

———. 2012. *On Being Included: Racism and Diversity in Institutional Life*. Durham: Duke University Press.

Andrews, Molly, Corinne Squire, and Maria Tamboukou. 2008. "Doing Narrative Research." In. London: SAGE.

Barnes, Colin. 1991. *Disabled people in Britain and discrimination : a case for anti-discrimination legislation*. London: Hurst in association with the British Council of Organizations of Disabled people.

Barnes, Colin, and Geof Mercer. 2003. *Disability*. Cambridge: Polity Press.

Beauvoir, Simone de, Constance Borde, and Sheila Malovany-Chevallier. 2010. *The Second Sex*. 1st American ed. New York: Alfred A. Knopf.

Butler, Judith. 2006. *Gender Trouble: Feminism and the Subversion of Identity*, *Routledge classics.* New York: Routledge.

Campbell, Fiona Kumari. 2009. *Contours of Ableism: The Production of Disability and Abledness*. New York: Palgrave Macmillan.

Corker, Mairian, and Sally French. 1999. *Disability Discourse*, *Disability, human rights, and society*. Buckingham: Open University Press.

Corker, Mairian, and Tom Shakespeare. 2002. *Disability/Postmodernity: Embodying Disability Theory*. London: Continuum.

Crow, Liz. 1996. "Including All of Our Lives: Renewing the Social Model of Disability." In *Encounters with Strangers: Feminism and Disability*, edited by Jenny Ed Morris, 206-26. London: Women's Press.

Davis, Lennard J. 2006. "Constructing Normalcy: The Bell Curve, the Novel, and the Invention of the Disabled Body in the Nineteeth Century." In *The Disability Studies Reader*, edited by Lennard J. Davis, 3-16. New York: Routledge.

Foucault, Michel, and Colin Gordon. [1972] 1980. *Power/Knowledge: Selected Interviews and Other Writings, 1972-1977*. Brighton Harvester Press.

Frank, Arthur W. 1995. *The Wounded Storyteller: Body, Illness, and Ethics*. Chicago: University of Chicago Press.

Goodley, Dan. 2014. *Dis/ability Studies: Theorising Disablism and Ableism* New York: Routledge.

Grinyer, Anne 2002. *Cancer in Young Adults: Through Parents’ Eyes*. Buckingham: Open University Press.

Harrison, Jack, Jaime Grant, and Jody L. Herman. 2012. "A Gender Not Listed Here: Genderqueers, Gender Rebels, and OtherWise in the National Transgender Discrimination Survey."  *LGBTQ Public Policy Journal at the Harvard Kennedy School* 2:13-24.

hooks, bell. 2000a. *Feminism is for Everybody: Passionate Politics*. Cambridge: South End Press.

———. 2000b. *Feminist Theory: From Margin to Center*. 2nd ed, *South End Press classics ;*. Cambridge: South End Press.

Hughes, Bill. 2002. "Disability and the Body." In *Disability studies today*, edited by Colin Barnes, Michael Oliver and Len Barton, viii, 280 p. Cambridge: Polity.

———. 2014. "Disability and the Body " In *Disabling Barriers - Enabling Environments*

, edited by John Swain, Sally French, Colin Barnes and Carol Thomas, 113-24. London: SAGE.

Hughes, Bill, and Ken Paterson. 1997. " The Social Model of Disability and the Disappearing Body: Towards a Sociology of Impairment."  *Disability and Society* 12:325-40.

Johnson, Merri, and Robert McRuer. 2014. "Cripistemologies: Introduction."  *Journal of Literary & Cultural Disability Studies* 8 (2):127-47. doi: <https://doi.org/10.3828/jlcds.2014.12>.

Kremer, William 2013. "Human Echolocation: Using Tongue-Clicks to Navigate the World." BBC, Accessed June 6, 2018. <http://www.bbc.co.uk/news/magazine-19524962>.

Kuppers, Petra. 2011. *Disability Culture and Community Performance: Find a Strange and Twisted Shape*. Basingstoke: Palgrave Macmillan Publishers.

Mallet, Rebecca, and Katherine Runswick-Cole. 2014. *Approaching disability: Critical issues and perspectives*. London: Routledge.

Masefield, Paddy. 2006. *Strength: Broadsides from Disability on the Arts* Stoke on Trent: Trentham Books.

McRuer, Robert. 2006. "Compulsory Able-Bodiedness and Queer/Disabled Existence." In *The Disability Studies Reader*, edited by Lennard J. Davis, 301-8. New York ; Abingdon, Oxon: Routledge.

Milligan, Christine 2005. "Placing Narrative Correspondence in the Geographer’s Toolbox: Insights from Care Research in New Zealand."  *New Zealand Geographer* 61:213–24.

Morris, Jenny. 1989. *Able Lives: Women's Experience of Paralysis*. London: Women's Press.

———. 1991. *Pride Against Prejudice: A Personal Politics of Disability*. London: Women's Press.

———. 1996. *Encounters with Strangers: Feminism and Disability*. London: Women's Press.

Oliver, Michael. 1990. *The Politics of Disablement*. London: Macmillan Education.

Paterson, Kevin, and Bill Hughes. 1999. "Disability Studies and Phenomenology: The carnal Politics of Everyday Llife."  *Disability & Society* 14 (5):597-610. doi: 10.1080/09687599925966.

Price, Margaret. 2011. *Mad at School: Rhetorics of Mental Disability and Academic Life*. Ann Arbour: University of Michigan Press.

———. 2015. "The Bodymind Problem and the Possibilities of Pain."  *Hypatia* 30 (1):268-84. doi: doi:10.1111/hypa.12127.

Rich, Adrienne 1980. "Compulsory Heterosexuality and Lesbian Existence."  *Signs: Journal of Women in Culture and Society* 5:631-60.

Riessman, Catherine Kohler 2008. *Methods for the Human Sciences*. London: Sage.

Santos, Boaventura de Sousa. 1994. *Pela Mão de Alice: O Social e o Político na Pós-modernidade*, *Biblioteca das ciências do homem. Sociologia, epistemologia ;*. Porto: Edições Afrontamento.

———. 2007. "Beyond Abyssal Thinking: From Global Lines to Ecologies of Knowledges."  *Review* XXX (1):45-89.

———. 2008. *Another Knowledge is Possible: Beyond Northern Epistemologies*. London: Verso.

Shildrick, Margrit. 1997. *Leaky Bodies and Boundaries: Feminism, Postmodernism and (Bio)ethics*. London: Routledge.

Siebers, Tobin. 2006. "Disability in Theory: From Social Constructionism to the New Realism of the Body." In *The Disability Studies Reader*, edited by Lennard J. Davis, 173-84. New York ; Abingdon, Oxon: Routledge.

———. 2008. *Disability Theory*, *Corporealities*. Ann Arbor: University of Michigan Press.

Slorach, Roddy. 2016. *A very capitalist condition: a history and politics of disability*. London: Bookmarks Publications.

Sontag, Susan. 1991. *Illness as a Metaphor and AIDS and Its Metaphors*. London: Penguin Books.

Squire, Corinne, Molly Andrews, and Maria Tamboukou. 2008. "What is Narrative Research?" In *Doing Narrative Research*, edited by Molly Andrews, Corinne Squire and Maria Tamboukou, 1-21. London: SAGE.

Thaler, Lore, Stephen R. Arnott, and Melvyn A. Goodale. 2011. "Neural Correlates of Natural Human Echolocation in Early and Late Blind Echolocation Experts."  *PLoS ONE* 6 (5):1-16. doi: 10.1371/journal.pone.0020162.

Thomas, Carol. 1999. *Female Forms: Experiencing and Understanding Disability*. Buckingham: Open University Press.

———. 2007. *Sociologies of Disability and Illness: Contested Ideas in Disability Studies and Medical Sociology*. Basingstoke: Palgrave Macmillan.

Titchkosky, Tanya , and Rod Michalko. 2014. "Narrative." In *Disability Studies: A Student's Guide*, edited by Colin Cameron, 101-4. London: Sage.

Tresniowski, Alex 2013. "The Boy Who Sees with Sound." People, Accessed December 5, 2013. <http://www.people.com/people/article/0,,1212568,00.html>.

Warner, Michael 1991. "Introduction: Fear of a Queer Planet."  *Social Text* 29:3-17.

Wendell, Susan. 1996. *The Rejected Body: Feminist Philosophical Reflections On Disability*. New York Routledge.

———. 2008. "Notes from Bed: Learning from Chronic Illness." In *Dissonant Disabilities: Women with Chronic Illnesses Explore their Lives*, edited by Diane Driedger and Michelle K. Owen, 209-18. Toronto: Canadian Scholars' Press.