This paper is based on research about the daily lives of people living with chronic illnesses in England and Portugal. Through the first-person narratives of participants, I argue that the lives of people living with debilitating chronic illnesses are affected by disablism, discrimination and exclusion. These aspects affect them in several important realms of life such as lack of or poor social support, difficulties in obtaining reasonable adjustments or the inability to obtain any kind of state support at all. These aspects are also widespread and compound and greatly influence their lives, beyond or in addition to the physical experience of the illness itself. I conclude that it is fundamental to change these structural and policy aspects and that people should have access to what I have termed a paradigm of sustained wellbeing, despite the illness.

Keywords: disablism; chronic illness; disability; sustained wellbeing; Portugal; England
Introduction

This paper will discuss the experiences of disablism reported by people living with chronic illnesses in England and Portugal. It is based on my research about the daily lives of people living with a chronic illness, in particular people living with Fibromyalgia (FM), Chronic Fatigue Syndrome (CFS), Myalgic Encephalomyelitis (ME) and Multiple Sclerosis (MS). This research used the narrative correspondence method (Milligan 2005; Grinyer 2002; Thomas 1999) to gather the personal accounts of a total of 32 participants in both countries. The study is firmly grounded on a disability studies and feminist perspective often referred to as feminist disability studies (Garland-Thomson 2005, 2006). This theoretical lens has been hugely influential in terms of the debates around chronic illness.

Whilst a significant part of the literature about chronic illness coming from a sociological perspective tends to focus on how the individual 'copes' and 'adjusts' their self to the onset of a chronic illness (Bury 1982, 1991; Charmaz 1991, 1983), perspectives in feminist disability studies have been extremely important in inviting an understanding of this issue from a disability rights perspective whilst, at the same time, also being mindful of the role of the body (Wendell 2008, 1996, 2001; Hansen 2008; Driedger and Owen 2008; Driedger 2010; Thomas 2007, 2012). Feminists in disability studies have made important contributions in regards to chronic illness, drawing mainly from feminist debates around embodiment. This literature has challenged the traditional sociological literature and brought about the need to understand chronic illness as a 'category of impairment' (Thomas 2007), from a disability rights perspective. This implies understanding chronic illness within the larger context of disability rights and the disabled people's movement. This matters because early debates in disability studies have sought to differentiate between disability and illness for important reasons (Wendell 2001; Barnes and Mercer 1996) namely the fact that all disabled people are often perceived as being ill instead of disabled by society. However, I argue that it is important to understand how people who live with illnesses or conditions that are not immediately cured, and are either chronic or recurrent, are equally affected by structural, cultural and external circumstances. In this regard, disability studies should not shun illness altogether and leave it be the realm of the medical model and medical institutions. It matters to consider how people living with these illnesses are not mere hostages of their bodies but might also be affected by a number of external, structural conditions that could be changed. In this research, then, I wanted to find out if people who
have chronic illnesses experience disablism and, if so, how this happens in their lives. Presuming that illness can always be ‘cured’ and, furthermore, that unlike other impairments, social, political and contextual issues have nothing to do with the experience of illness, is a dangerous argument. This paper intends to question these premises and offer insight into what influences and affects the lives of people who are chronically ill.

It should be mentioned that the term chronic illness is being increasingly abandoned by officials in favour of chronic disease or long term health condition, which encapsulates diseases such as hypertension, depression, cancer and asthma (Partnership to Fight Chronic Disease 2009; Long Term Conditions Team 2012). I chose to use chronic illness because it is the term predominantly used in previous disability studies literature and also, crucially, it is the term widely used by the community of people who live with these conditions which mattered quite a lot to me as a researcher who also identifies as a disabled person living with a chronic illness.

Even though the research employed what I term a constellation approach, explicitly engaging with several different aspects of living with a chronic illness, instead of focusing just on solely one single angle of view, in this article I will focus exclusively on the experiences of disablism reported by participants in both countries and contextualize these. As Thomas mentions ‘disablism . . . refers to the social beliefs and actions that oppress/exclude/disadvantage people with impairments’ (Thomas 2007, 13). This paper, then, intends to shed some light into these aspects by also making use of participants’ accounts.

**Methodology**

This research employed narrative methods to solicit first-person accounts from participants in England and Portugal. In order to elicit the personal accounts of people living with a chronic illness in England and Portugal, I chose to use the narrative correspondence qualitative research method (Grinyer 2002; Milligan 2005; Thomas 1999) – based on inviting and analyzing the experiential accounts written or recorded by a sample of people with chronic illnesses in both countries. In this case, participants were invited to submit their written or oral accounts through a specially-built online submission form included on a website localized for each country. After receiving participants’ accounts I also asked them further questions via email in order to invite them to elaborate further or clarify particular issues they had raised. Submissions through the website were accepted for a period of 4 months (from
February 2011 to the end of May 2011) and email conversations with participants continued for another 3 months.

I wanted to use this method in part because I liked how it relied on participants wanting to come forward and take part in the study while choosing to share what they thought was important. I also liked that participants would have some control of what they wanted to say, even though, of course, ultimately I had the power to edit their words and select which contributions to include. I also thought this method would allow interested parties to take part according to their own timing. Due to the unpredictable nature of these illnesses, it was also possible that some people might be too tired or ill to be able to schedule an interview but they might be willing to write or record something on their own time.

I began by circulating a research information sheet 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 people were welcome to tell me about any aspects of their lives that they wished to share. This was circulated via email, through patient associations and online groups as well as through internet forums and websites in both countries.

In terms of data analysis, I used thematic analysis to organize accounts in to themes and I then defined subthemes. This paper 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 here 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. In this paper I take participants’ accounts as a starting point but I do contextualize their words by also drawing from documentation such as social policy and legislation (Scott 2006; McCullock 2004).

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.

A transnational study

As mentioned before, the study focused both in Portugal and England. I chose to focus on England only (as opposed to the whole of the UK) because I wanted to focus only on one legislative context as this would allow me to compare the context of the two countries more easily. The comparison between England and Portugal in terms of disability is a fruitful one because there are significant differences between the two countries in terms of social policy approaches to disability. The same is true in terms of the organization and presence of the disabled people's movement which in Britain has had a long historical presence but in Portugal, due to historical circumstances such as the dictatorship, has developed much later and with different characteristics (Fontes 2008, 2011). It is also important to understand that the characteristics of the welfare state that exists in Great Britain and other central European countries are very different from the characteristics of the welfare state in a much poorer country such as Portugal.
The comparison between the two countries also allowed me to grasp the role of cultural codes and norms across cultures and see whether these would be very different or whether there would be common things reappearing across different cultural contexts.

**Disablism in the context of employment and state support**

The external social and structural context of support that is available to people living with chronic illnesses is crucial to investigate because the embodied experience of living with these illnesses can be onerous and complicated enough to manage. However, it is also essential to look at the role of external aspects and circumstances and how these frame the lives of these people. Taking a closer look at the context of employment and state support provides an interesting vista to analyse the impact of some of these aspects in people's lives. In this section, I will draw from a number of narratives that illuminate important aspects of people's lives in regards to employment and state benefits in both countries.

Many participants in this research, from both countries, highlight some of the challenges and difficulties they experience, including difficulties of a financial nature, after being faced with illness. The role of employment and the importance of social benefits and state support were therefore significant themes in the narratives of participants in this study although this manifested in slightly different ways in both countries, as I will detail below.

Although in England it has been possible for people living with chronic illnesses to apply for some state support in the form of benefits, along with other disabled people, this type of social support has been strongly eroded in the last few years in a fundamental and profound way (Cross 2013; Morris 2013; Harwood 2014). Changes in benefits, such as the end of Disability Living Allowance (DLA) and the introduction of Personal Independence Payment (PIP) as well as the closure of the Independent Living Fund (ILF), have meant that many disabled people had to be reassessed and either lost their benefits altogether or were moved to Employment Support Allowance (Cross 2013; Morris 2013; Harwood 2014). It is beyond the scope of this article to describe these changes in detail. It is also not the main purpose of this article to present a detailed analysis of disability policy in England and Portugal and there are many excellent sources of this (Fontes 2011; Oliver and Barnes 2012; Roulstone and Barnes 2005; Roulstone and Prideaux 2012; Pinto and Teixeira 2012; Portugal et al. 2010). My purpose here is to focus on how the study's participants were keen to report the impact of state support and benefits (or lack thereof in their lives) since in England, at the
time that the empirical work was taking place, the recent government measures regarding state benefits for disabled people were beginning to take shape.

**A difficult process to obtain benefits in the English context**

Some participants living in England were keen to share their accounts of interactions with the benefits system at that time or reporting recent events that had happened in this context. One of the issues reported by participants, particularly for those who were able to access some benefits, was the fear of being reassessed as being fit for work and having their circumstances changed suddenly. One of my participants, Susan, summarized this issue well when she mentioned that:

> Money: benefits are under threat now due to the Government’s overhaul of benefit allowances, due to my fluctuation of energy levels, cognitive problems, depression, [I am] worried about the knock on effect if benefits are reduced. Also have been assessed several times and have already been told you will never work again! But the government seem to think otherwise! (Susan, Female, England, 51-60, Myalgic Encephalomyelitis)

This was a real worry for many people and there is an aspect of instability and arbitrariness in these changes that was very worrying for many participants. People living with these illnesses often experience inhabiting in-between spaces as some of these illnesses do not always have visible signs of impairment and thus others might not perceive people as being disabled or in need of support. This is an issue as well for the encounters with the privately contracted medical panels in England (first Atos and now Maximus) where disabled people are asked to fit into particular boxes that have to be ticked in order to be able to receive social support – a process that has been criticized by disabled people and health professionals alike (Department for Work and Pensions; Office for Disability Issues 2014; Cross 2013).

The process of obtaining benefits itself can be harrowing for some people and leave them drained. People who live with chronic illnesses are already battling debilitating symptoms that have a real effect on their lives, having to deal with the suspicion of the state only adds to the stresses and complications of their already difficult lives. This was
particularly illuminated by a narrative I received from an English participant who had faced a struggle when dealing with the Department of Work and Pensions. Mick, who lives in England and has Multiple Sclerosis (MS), focused his account initially on the difficulties he had in trying to obtain support from the state after his employer let him go for having been diagnosed with MS. He reports his interactions with the Department of Work and Pensions as very stressful and unsupportive, at a time when he desperately needed support and guidance after being faced with his new diagnosis:

My employment in the British merchant navy required that on diagnosis I declare to the government my MS and have an official Maritime & Coastguard Agency (MCA) Medical. This was undertaken and I was declared permanently unfit for service....This was after a career spanning 37 years............ My employer could not keep me on so this meant I lost my employment at sea. Going to the DWP [Department of Work and Pensions] I was among the first to experience (back in 2008) the new ESA [Employment and Support Allowance] route .......... No reference to this earlier medical was ever made and I eventually attended the ATOS Medical where I was awarded 21 points which placed me in the 'support group' [15 points were required to qualify for the benefit]. This process [with the Department of Work and Pensions] took several months and involved me with a huge amount of stress (not helping the MS) Finally at the end of the process DWP declared I was on ESA [Employment and Support Allowance] BUT only as a person being credited with NI [National Insurance] contributions. This means I am not entitled to receive any money from ESA as the benefit is means tested and I had correctly told them of my exact situation regarding savings and pension.......... This was a big shock. Why Oh Why could they not have said that in the first place !!!!!!!!!!!!!!!!! (Mick, Male, England, 51-60, Multiple Sclerosis)

Mick's account also highlights the recent changes in disability policy in Britain as many people who previously were on Incapacity Benefit or Severe Disablement Allowance were moved to Employment and Support Allowance (ESA). In his case, even though he had paid National Insurance, because ESA is means tested and his employment history in the merchant navy meant that his work contract was via the Channel Islands, the DWP did not award him
any ESA support. Accounts such as Mick's also illuminate the stress involved in dealing with the benefits system at a time when many people's lives might be already in turmoil due to the onset or development of illness – this is a serious issue that needs to be considered carefully because it adds an extra layer of difficulty to people's lives at an already difficult time as Mick again illustrates:

The lack of support from the government truly shocked me!!! AND STILL DOES! I had never been unemployed in my life and had always paid tax and NI ............... It felt so awful dealing with the DWP and without assistance there is simply no chance of being dealt with fairly! This had a huge negative impact on my life for the first 2 years of my diagnosis. ... The DWP is a shambles when it comes to proper assistance. . . . All in all it was some battle! These aspects greatly interest me now and the importance for the newly diagnosed in having some contact with other people in the same situation is so important. (Mick, Male, England, 51-60, Multiple Sclerosis)

Several participants' accounts, illustrated well here by Mick's narrative, mention the frustration of not being recognized as a 'worthy' citizen and contributor by the state. After working for decades on a demanding job, Mick really conveys the frustration of having to deal with a state that seems to imply many disabled people are just 'takers' and that questions their need to obtain a very basic level of support that simply allows them to barely survive.

**The impossibility of retirement or state support for some in Portugal**

When it comes to Portugal, the situation regarding disability benefits, particularly those affecting people living with chronic illnesses is very complex. Rights for disabled people in Portugal have tended to be achieved for particular groups such as War veterans who then might have specific legislation created that pertains to that particular population but not to others. Fernando Fontes, who has done extensive research about Portuguese social policy, considers that there is a ‘piecemeal approach to disability policy’ in Portugal since there really has not been an integrated and coherent set of policies (Fontes 2011, 127). This is noteworthy because it also means there is no single set of laws that address disability as a multi-categorical site such as the Equality Act or the Americans with Disabilities Act. This is not to say that these types of legislation are unproblematic or that they address all the issues
required by disabled people, or indeed that they bring real equality and autonomy for disabled people. In fact, often they arguably do not significantly change disabled people’s material conditions. However, they do provide a certain level of basic protection under the law that is important, especially comparing with contexts such as Portugal where this does not exist in the same way (Lawson 2008; Lawson and Waddington 2009).

Likewise, in terms of the situation of people with chronic illnesses more specifically, some social rights in Portugal have been achieved through targeted legislation for some groups of people, for instance, people diagnosed with Multiple Sclerosis, but other groups of people living with chronic illnesses have been virtually unprotected. This is a very important aspect to consider and it means that people living with specific chronic illnesses might have virtually no possibility of accessing state support of any kind. These aspects are reflected in the narratives sent by the Portuguese participants. Another important aspect to note is that the effects of austerity measures imposed on Portugal and other southern countries further negatively impacted the promotion and protection of disabled people’s rights (Pinto and Teixeira 2012, 14).

One of the issues that was raised by participants concerned some people feeling trapped between the need to have a job and the debilitating effects of the illness meaning they might have periods where they might not always be able to work or they might not be able to work in the same way they did before. This brings about a situation that can be hard to navigate for some people and means people need to do the best they can in the circumstances they were given. One of the Portuguese participants who called herself Misa, illustrated these aspects well when she reported that, after being diagnosed with fibromyalgia and chronic fatigue syndrome, she lost her job which involved doing quite a bit of heavy physical work, due to the fact that she could no longer do that type of work or endure the long drive to the workplace. Her employers refused to provide reasonable adjustments or move her to another position within the same institution, even though she had requested this as a way to be able to continue working. According to Misa, this was due to the lack of acknowledgement that illnesses such as fibromyalgia have in Portugal. This type of refusal is not difficult for employers to do since the concept of reasonable adjustments, as it exists in the UK, was never transferred into the Portuguese legislation in the same way, although the law does forbid discrimination due to disability (Lawson and Waddington 2009). Misa explains her employer’s reaction to her requests:
There were a lot of apologies, they said there was no reason why I could not come back to the work I was doing. They said I did not have any work because I did not want to work. I had to stay home because I did not have the necessary conditions to be able to work and had absolutely no support of any kind. . . . It’s a big fight because the illness is not accepted or recognized as incapacitating in Portugal. I can only rely on my family for help and I just hope that one day we will achieve our rights. (Misa, Female, Portugal, 41-50, fibromyalgia, chronic fatigue syndrome)

Misa thus recounts being out of work with no benefits of any kind and relying only on the help of relatives to get by – a very difficult situation for anyone. It is fair to speculate that if a different type of legislation were in place to accommodate the needs of Misa in the workplace, her situation might have been different, which is not at all to say that all situations are ameliorated or resolved by legislation alone.

In addition, the fact that Misa resides in a very rural setting seems to have made her life even more difficult compared to those who live in a city since she found herself with less choices even in term of treatments to try to alleviate her symptoms as she became unable to drive long distances to be able to do things like swimming. This is an important intersection to bear in mind, since the kinds of infrastructures such as pools, public transportation or other resources available tend to be less for those living in rural places, thus exacerbating some of their circumstances.

The other worrying aspect present in some of the narratives received was the fact that many Portuguese participants reported being unable to receive reasonable adjustments at work and therefore they felt the only viable option for them was to quit their jobs. However, they were also unable to retire due to illness. Therefore they would find themselves in a very difficult situation where no options were present and no possibilities were envisaged. This is one of the most difficult situations that participants reported and is well illustrated here again by Misa's account. After being unable to receive reasonable adjustments of any kind at work, and, therefore, being suddenly without any income, Misa tried several times to apply for a state pension and retirement on the grounds of disability, which in Portugal means having to attend a medical panel. Her request was refused by the medical panels several times but she detailed the painful process of having to participate in this process:
In what concerns medical panels: it was a very painful process for me. The doctors would sometimes have a certain smirk in their faces and to them Fibromyalgia simply does not mean anything. I had to travel 400km [about 248 Miles] to be able to attend the panel because you have to go to Lisbon [Portugal’s capital]. Then I would have to wait for hours and they would see me for no more than 5 minutes, at the most. The doctors do not read the reports [written by GPs or consultants], they do not see the exams. As soon as I would mention fibromyalgia, they would immediately tell me to go back to work.

They always tell me that this illness is not a cause for retirement and sometimes, some have been really rude to me. After each trip, I would sometimes spend weeks in bed without being able to even get up. I do not understand why some people behave in certain ways, including doctors. It is very painful to experience these kinds of things and it makes me angry. Psychologically, this process has been extremely taxing for me and one wastes the little energy one has to fight against all of this. I am very thankful for our exchange because it allowed me to talk about things and it gives me hope that one day people can understand the illness and treat us in the way we deserve to be treated.  

(Misa, Female, Portugal, 41-50, fibromyalgia, chronic fatigue syndrome)

Even though she reports having detailed reports from her GP and hospital consultants concerning her inability to work due to the illnesses that affect her, she reports that was not at all taken into account by the medical panels she has attended.

Portuguese law stipulates that someone can only request a pension due to ‘invalidity’ or old age, the terms of which are explained in Law-Decree 187/2007 (10/05/2007). The law clearly mentions that ‘permanent incapacity’ for work is essential and that this can only be assessed by medical professionals, with the last word given to the medical assessment panel. Since Misa recounts that she has repeatedly been considered fit for work by the several panels she attended, she is unable to retire due to illness. She would also not be able to retire due to disability because this is subject to a very defined list of impairments and ‘incapacities’ as well as an assessment of the ‘degree of incapacity’. This would be the same for other people in similar situations.

Her story really calls one’s attention to a very binary ‘either/or’ system that heavily penalizes people living with fluctuating chronic illnesses. People are expected to perform ableist modes of work and when they are unable to do that and try to seek a state pension they
face being ridiculed and even mistreated. The result is that some people in Portugal have literally nothing to fall back on – no safety net of any kind. Some people are not considered ill enough to get a pension and they are also not able to or supported enough to be able to work. This is perhaps another feature of the common assumption that someone is either permanently ill or permanently incapacitated. The end result for someone like Misa is that she reports she is presently without any income. As Dan Goodley argues, ‘Disabled people are caught in a catch-22: either to show they are really disabled (so welfare dependent) or emphasise their readiness for work (where their benefits are reduced as they try to access an ever more competitive, aggressive, flexible, low-paying and . . . ableist labour market).’ (Goodley 2014, 10). People are placed in a situation where they just cannot win. A significant change will not happen unless we understand and accept that ableist work practices and ability expectations cannot be imposed on people with these conditions in the same way – their needs and abilities need to be assessed and put into practice in a way that works for them.

*Externally imposed impairment effects*

The narratives shared so far relating to both England and Portugal all highlight an important aspect that is worth noting. Participants report how, on top of their impairments and impairment effects, they have to live in stressful conditions and go through unavoidable physical activities that actually increase their symptoms. The supplementary stress experienced by people or the unnecessary extra actions they have to do to try to obtain what should be basic rights actually can then *worsen* the impairment effects people experience – something that disability studies should also be looking at more carefully.

The concept of impairment effects has been proposed by Carol Thomas who defines it as ‘the direct and unavoidable impacts that impairments (physical, sensory, intellectual) have on individuals’ embodied functioning in the social world. Impairments and impairment effects are always bio-social in character, and may occur at any stage in the life course’ (Thomas 2010 – author’s emphasis). This definition calls our attention to the bio-social nature of impairment effects, since neither impairments nor their effects can be reduced to mere biology. They are corporeal but *also* social in nature and they depend on the interactions with the environment. Drawing from Thomas, I argue that the situations described by participants such as Mick and Misa can be seen as *externally imposed impairment effects* –
these are impairment effects such as pain, fatigue, tiredness or soreness that are actually created or exacerbated by the painful interactions disabled people are required to have with the state, doctors or other institutions. In the examples above, both Mick and Misa report experiencing a worsening of symptoms that could have been avoided had they not had to deal with those institutions in such a stressful way. The fact that Misa had to drive many miles to attend a medical panel that reportedly lasted 5 minutes, clearly created symptoms that Misa had to cope with for days to come and that could have been avoided in the first place.

_Having no options left_

If the situations presented previously are difficult, there were other accounts that really highlighted the fact that some people living with these chronic illnesses are really unable to maintain a job of any kind but are also unable to find any kind of support whatsoever which really places them in tremendously precarious situations. One of the accounts I received from Portugal really illuminated this difficult circumstance. Rosa, a Portuguese woman who had tried to do several jobs but found herself really unable to work, focused part of her account on the enormous difficulties of facing a life without any support and being entirely financially dependent on her family:

My problem throughout the years in Portugal has been and still is: how will I survive? I am talking about the most basic things necessary. Financially. Because I am not entitled to a pension. It is a very precarious situation. During the last few years I have not been able to work and unlike what takes place in other countries, at least Western countries, I am not entitled to receiving a pension. . . . This is a crime against human dignity. The fact is that I do not have a husband that supports me and would allow me to have legal rights. . . . I have this great fear that is like a huge, heavy monster that hunts me: how will I be able to survive? I am not able to work. Many times I am bed-ridden and I wonder how will I be able to do basic things and survive financially? . . . Some days I am very affected by these thoughts and I fight against it. . . . [Since I got worse again] my only source of income is selling unwanted goods online in auction sites. This has been important to me because I am able to do what is required. Even when I am terribly ill, if someone bought something and I have to send it to them, I drag myself to the post office because it is important to me. But this is something that doesn’t happen a lot.
Maybe I am able to sell something every couple of weeks or so. (Rosa, Female, Portugal, 31-40, Fibromyalgia)

Rosa’s account really demonstrates the despair felt by many people who are in this situation and have to face a life without any social support. It is interesting to note that she uses quite a strong expression to describe the lack of support available to her and other people in her condition in Portugal, she calls it a ‘a crime against human dignity’. This is a strong reminder of the fragility felt by some people in face of a situation that they are unable to control. In her case, it seems she is not in a worse situation because she is living with her family but for someone who might have no family that is able to support them, a similar situation could be completely disastrous. Even in her case, there is a basic wish for dignity that all human beings have that is hard to achieve when one is being supported by others. This is perhaps highlighted in her desire to sell things online as a way to earn some minimum income.

In Portugal there is no state support available for people in Rosa’s situation. The situation regarding benefits in Portugal is very complex and often very different in different situations. As Fernando Fontes mentions in his detailed and expert analysis of Portuguese disability social policy, people who are impaired at work are expected to be protected by private insurance companies and the state does not contribute in these cases (Fontes 2011, 113). For those disabled people who have some social security contributions and who are considered permanently unable to work and whose impairment was not caused by a work accident, there is an Invalidity Pension available. Access to this pension is controlled by medical professionals according to the National Chart of Impairments and it is almost impossible for someone with illnesses such as fibromyalgia or chronic fatigue syndrome to have access to this pension because such health conditions are not listed in the chart. For those disabled people who have been unable to work and pay social security at all, an invalidity social pension is available. As with the previous situation, disabled people must be assessed by medical professionals and their impairment must be listed in the National Chart of Impairments. There is also another kind of support called Special Invalidity Protection which helps people with very specific progressive and degenerative illnesses and covers people living with Machado-Joseph Disease, HIV-AIDS, Multiple Sclerosis, oncologic diseases, Parkinson and Alzheimer. However, according to a very recent update to this legislation (Law 6/2016 – 17/03/2016) this only applies if it can be proven that someone’s illness is evolving towards a situation that would lead to a complete loss of autonomy and
impact negatively on a person’s ability to work. Therefore, for instance, someone living with MS would not be able to have this support whilst they remain fairly active and illnesses such as ME and CFS are not part of the conditions considered relevant here as the legislation targets particular illnesses instead of being all-encompassing. Also, the law’s new focus on loss of autonomy would be very hard to apply to fluctuating conditions. Fontes argues that none of the existing support in Portugal is rights based but rather very much based on a bodily deficit model which is of course very problematic. He goes on to say that the existing level of support is extremely low for all disabled people who are seen as passive recipients instead of active citizens, therefore disabled people have little access to cash benefits or disability support services (Fontes 2011, 121-123).

For most disabled people the support available allows them only to live in poverty, on the other hand, for people living with chronic illnesses support is only available for selected illnesses and in extreme cases which means people are entirely dependent on the benevolence of medical panels to obtain certain benefits and, in some cases, this is not achievable at all regardless of how poorly someone is doing, as illustrated by Misa’s narrative. In other cases, someone like Rosa will not even be able to attend a medical panel at all since she has not been able to be in employment but she also will not be able to qualify for any kind of social support either.

**Conclusion: towards a paradigm of sustained wellbeing**

Based on participants’ narratives and my analysis of social policy and legislation in both countries, I argue that being able to access state support is fundamental for many people living with chronic illnesses as in some cases people, such as Rosa, are unable to work and are left in very precarious situations. In addition, participants point to the importance of legal and social policy frameworks that work for them when it comes to social support and access to employment. Thus, some people, like Misa, reported not being able to retire in Portugal but also not being able to access reasonable adjustments at work and thus finding themselves between a rock and hard place.

Other participants felt they had no choice but to use sick leave to try to get by when they could not cope with the symptoms of the illness. However, this has very serious monetary consequences for them since they end up with very little money when they do this. These models of sick leave do not take into account chronic conditions, forcing people into
structures that were not designed with them in mind. Sick leave should also take into consideration that many people will have periods of illness which are recurrent but might want to return to work. Strict models of the ‘sick role’ (Parsons [1951] 1964), which assume sickness followed by restoration of health really are not helpful in this context and can be counterproductive for people living with chronicity of symptoms.

Furthermore, being faced with not being able to work but also not being able to obtain support from the state places people living with chronic illnesses, such as Mick, in a situation of extreme endurance. The costs of being disabled in a society that disables people are already enormous, not just in terms of mere survival, but also in terms of all the aspects necessary to live a life that is filled with obstacles and disabling practices and spaces. Likewise, I argue that the present neo-liberal rhetoric currently embraced in Britain by the Conservative Government around disability and benefits remains restricted to the neoliberal and Judaeo-Christian ideology that work liberates people from the circumstances of their existence and provides a way to 'overcome' the 'disability' therefore creating an illusion of personal responsibility at all costs that should supposedly place personal 'effort' over collective care and responsibility.

Scholars in disability studies have argued since the 1970s that work and access to work were at the heart of disabled people's exclusion, since many impairments could be easily accommodated by employers (Oliver 1990; Barnes and Mercer 2003). However, work does not, per se, eliminate the obstacles of a disabling society that keeps excluding disabled people at all levels from education to the built environment to cultural practices. Furthermore, the context of employment remains problematic for many disabled people due to the fact that disabled people and people with chronic illnesses are simply expected to fit the existing ableist normative box of expectation and demands that has been built around the mind/body configurations of non-disabled people. Some disabled people and scholars in disability studies have questioned some of these issues in a significant way arguing for the need to think about the role of work in another way (Graby 2015; Price 2011; Barnes 2012).

The research strongly indicates that the lives of people living with chronic illnesses featured in this study, namely Multiple Sclerosis (MS), Chronic Fatigue Syndrome (CFS), Fibromyalgia and Myalgic Encephalomyelitis (ME), are layered by patterns of disablism (and ableism). Furthermore, the effects of disablism are onerous, widespread and compound thus they directly influence people’s standards of wellbeing, despite the effects of illness. It matters to be aware of these and how much they affect people’s lives because such aspects
can be changed, unlike other aspects such as illness symptoms. In other words, within the constellation of factors that interact in the experience of chronic illness, the ones related to legislation, social policy and benefits really influence people’s wellbeing and at the same time they are not fixed aspects as is the case with other embodied aspects of the constellation. Further, from the analysis of participants’ narratives it is possible to conclude that disablism is present in several ways in the lives of people living with chronic illnesses and this is an important aspect to attend to. I argue that when the basic needs of people with chronic illnesses are being ignored by the state, such as through non-existent or unhelpful social policy or by removing or withdrawing social services and benefits, that means people with chronic illness are being socially excluded and discriminated against. When basic access to resources such as benefits is not in place or people’s very real material needs are questioned and ridiculed by the state and other institutions, that constitutes a violent process of exclusion and disadvantage for people living with chronic illnesses which is unacceptable.

The narratives of British participants in this study, such as Mick and Susan, showed that whilst some had been able to access benefits in the past, others were being asked to go through very difficult processes to access their current needs whilst many expressed concern they would see benefits taken away. Certainly, the comparison between both countries allows us to have a glimpse of where the situation for disabled people in Britain and people living with chronic illnesses might end up if the current attack on benefits and social support continues. The situation in Portugal, on the other hand, illustrates how in countries where people living with chronic illnesses have very little to none social protection and legislation, people often find themselves in dire straits living very pauper lives or relying entirely on the benevolence of family for basic support.

Many participants spoke in detail about how difficult it was to deal with life day by day. The effects of these illnesses can be extremely debilitating and therefore they can effectively affect people’s ability to function at several levels. Some spoke in great detail about how hard it was to take care of themselves at a very basic level, such as being able to attend to personal hygiene and perform basic tasks most people take for granted like being able to eat or wash their hair. For some of these participants being able to access care and social support would be essential. For many people living with chronic illnesses it is not a luxury to be able to access benefits, it is a necessity that will allow many to have access to basic human rights and a basic threshold of dignity. Access to benefits for disabled people living with chronic illnesses should not be part of political choices or economical reasoning.
It should be a standard practice of any country that places the wellbeing of its citizens at heart. These aspects also remind us of the importance of thinking about chronic illness from a disability rights paradigm. Thinking in a collective way about what we can do to ameliorate the social situation of all disabled people who experience disablism and discrimination in an ableist world is a much better model than focusing on the needs of each impairment or illness and trying to fight a lonely fight.

Lastly, many people and institutions still associate illness with a paradigm of cure. However, in the case of chronic illnesses, we are in the presence of conditions that are life-long and often unavoidable. I argue that conceptualizing this experience through a paradigm of sustained wellbeing is a better route. This paradigm understands that someone can be ill but still have a good standard of wellbeing by having access to good medical care and good social support or good reasonable adjustments at work that supports them to be able to have the best possible life. This paradigm also understands that someone’s experience is multi-layered and whilst their body/mind plays a role, cultural, societal and structural factors can make a difference between someone having a good standard of life, despite the illness, or living in extremely difficult circumstances. A paradigm of sustained wellbeing invites the notion that we are all interdependent and that there is a collective responsibility to respond to the needs of everyone and not just those who possess selected/particular abilities. It is focused on creating not just conditions for mere survival but for true wellbeing.

References


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