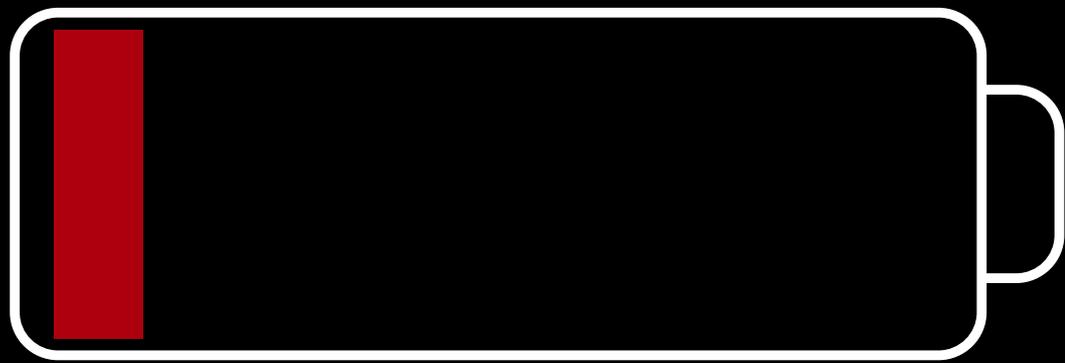


Energy Impairment and Disability Inclusion

TOWARDS AN ADVOCACY MOVEMENT FOR ENERGY LIMITING CHRONIC ILLNESS

by Catherine Hale, Stef Benstead, Jenny Lyus, Evan Odell and Anna Ruddock



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FOREWORD



Here are the voices of some of our focus group participants, introducing the main themes of this report:

I volunteered for this study because I'm frustrated by our society's approach to the chronically ill. We're treated as an encumbrance when all we want is to be able to live a normal life.

My 'real' disability is one that very few people know about and which I'm sure would not entitle me to use the word 'disabled'.

Everyone knows what it's like to be tired, so they think they understand the fatigue levels associated with chronic illness when they really don't.

Fatigue is brutal. It's not being tired and no amount of rest helps. Even holding your head up is a chore.

There's a lot of stigma to putting yourself in the disabled category if the person you're talking to disagrees with you being there.

I feel like every day I am battling to prove myself - that I am really this sick, that I am working hard, how exhausted I feel, how difficult things are for me, in order to avoid their judgements.

*It has taken me a *long* time to realise what help I can get [...] This was down to me not thinking of myself as disabled, so I just thought I'd struggle through it or avoid going to things... Using the term 'disabled' [...] means I can have my life back... Looking back, had I asked for more help and accepted my disabilities I could have saved myself a lot of pain, fatigue and emotional stress.*

None of the systems I have to interact with seem to be designed with people like me, who have chronic illnesses, in mind. Some of the consequences of that have damaged my health and put me in danger.

No matter how many adjustments may be required by the external world it makes little difference if you are too unwell to get out of bed.

I loved my work and now I'm no longer able to work I feel I have no place in society... Most of my friends and family have fallen away now and I rarely hear from them. This really upsets me but I understand that people are busy.

I feel isolated and alone, with no support.

I think the biggest difference would just be being believed and feeling more deserving of respect in society, instead of feeling like I need to be constantly on the alert and constantly fighting my corner against people's judgements and misinterpretations.

EXECUTIVE SUMMARY

About the Project

The Chronic Illness Inclusion Project (CIIP) ran from 2017 to 2019 as part of the DRILL programme of research led by disabled people, for disabled people. We looked at the experience of chronic illness as a type of disability or, in the language of the UK Disabled People's Movement (DPM), as an 'impairment group'.

The CIIP was a programme of emancipatory research, aiming both to produce knowledge about people with chronic illness, and to begin to transform that knowledge from an individual experience into a collective struggle for change. Our research agenda evolved from the researchers' lived experience of chronic illness, and their involvement in internet-based peer support networks and communities for chronic illness. It culminates in a manifesto for equality and inclusion, to be launched alongside this report.

We found compelling evidence that there is common experience and shared knowledge among people with chronic illness that is not heard or represented beyond our online networks, despite being a large subsection of the disabled population. The aim of this report is to bring the knowledge of the 2,300 people living with chronic illness who took part in our research closer to those who make decisions about our lives. Just as importantly, we propose strategies for amplifying our voice going forward.

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Aims and methodology

The CIIP was different from other patient-led initiatives whose focus is to advocate for improved medical care. As 'insider' researchers, we believe that experience of living with chronic illness can, and must, be transformed by changing the way society responds to us as disabled people, as well as through advances in medical treatment for particular diseases. For this reason, we aimed to follow the principles of emancipatory disability research.

Emancipatory disability research has been underpinned by a social model of disability. The social model has many strands but at its core is a distinction between 'impairment' and 'disability'. Impairment is the restriction caused by malfunction of body or mind, while 'disability' is restriction caused by factors external to the body/mind; barriers within the material environment, cultural attitudes and social organisation.

It can be difficult to disentangle the biological from the social causes of disadvantage and exclusion in any given case. However, we believed that exploring this distinction between impairment and disability in the experience of chronic illness would help us identify, and thus, challenge, the forms of social oppression that restrict and diminish our lives over and above our illnesses and diseases themselves. Therefore, the impairment/disability distinction framed our research questions, and it informs the structure of this report.

Chapter One deals with experiences of impairment with chronic illness: what is it about our conditions that restricts activity and wellbeing in and of itself; and who do we include under the ‘chronic illness’ label?

Chapter Two looks at experiences of disability, or what is more commonly referred to as ‘ableism’, with chronic illness. What are the ‘barriers’, whether material or cultural attitudes, that restrict or oppress us as disabled people?

Chapter Three discusses the implications of this knowledge for taking collective action. We explore how communication strategies could support a more effective advocacy movement for chronic illness. We ask what participants’ priorities are, in terms of social issues and public policy, for improving our lives.

We heard from hundreds of people in the online chronic illness community, in a programme of research designed to capture the breadth, as well as depth, of their knowledge. An extended qualitative research forum, or ‘focus group’, made up of 20 people and lasting eight weeks, allowed in-depth exploration of individual experiences. It took place on a tailor-made online platform, enabling us to reach people who would have been excluded from traditional face-to-face focus groups. A follow up survey designed to test and validate this experiential knowledge yielded 2,300 responses.

Chronic illness and the DPM

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Investigating a social model of disability in relation to the experience of chronic illness lays bare certain tensions and challenges. The concept of chronic illness is largely absent from both Disability Studies and disability activism in the UK. This occurred as ‘chronic illness’ became associated with an oppressive, medical model of disability. Indeed, many feel that chronic illness and the social model of disability are conceptually incompatible. On the one hand, some in the DPM think people with chronic illness focus too much on impairment – on restriction, suffering and the pursuit of medical intervention – and see this as a betrayal of the social model of disability. On the other hand, people with chronic illness think the social model does not apply to them because addressing external barriers and discriminatory attitudes doesn’t mitigate the impact of chronic illness enough to allow for social participation and inclusion. Thus, chronic illness and disability have been conceived of as different states.

We feel that these conceptual tensions create an impasse that prevents people with chronic illness from identifying and challenging the social and structural causes of our disadvantage. This makes it harder to claim our rights as disabled people. The aim of the CIIP was to explore whether and how the social model could be harnessed productively to support our own emancipation as disabled people.

Chapter One - A hidden impairment group

This chapter explores a) what it is like to live with chronic illness, and b) who we mean by the 'chronic illness community'. It presents first-hand accounts from our focus group participants, followed by quantitative data on impairment type, disability status and medical diagnoses and classification from survey respondents.

We explored the lived experience of impairment among people who identify as having chronic illness, as distinct from medicalised accounts of their illnesses and diseases. Despite their diverse symptom clusters, a surprising consensus emerged among focus group participants (who were selected for their broad range of diagnoses). Limited energy and fatigue were by and large the most debilitating and restricting feature of their chronic illness. This finding was corroborated by the survey, where almost three quarters of respondents selected the category 'stamina, breathing fatigue', to describe their impairment, and where fatigue or energy limitation, followed by pain, were rated as the most restricting symptoms.

Our focus group participants found common ground in their experiences of day-to-day life and the difficulty of conveying these experiences to others. They agreed that pathological fatigue is very different to the universal experience of 'tiredness'. Living with chronic illness, they reported, means carefully rationing scarce units of energy to get through each day.

Compared to many other forms of impairment, pathological fatigue is fluid in nature. Its impact on activity can't be isolated to one bodily or mental function because fatigue impacts on all functions, physical, cognitive and sensory. As a result, participants felt that the pathological fatigue they experienced did not meet the socially constructed definition of, and expectations around, 'disability' as a fixed state of incapacity.

Nearly three-quarters of our survey respondents described their impairment type using the category of 'stamina/breathing/fatigue' (SBF). According to government disability data, impairment of SBF is the second largest group among disabled people in the UK. Yet, in many ways SBF is a hidden impairment group. This is not only because fatigue is invisible. It is hidden because government departments formulating policies for disabled people, such as social security, employment and social care do not capture, or account for the needs of, people with SBF difficulties. It is hidden because organisations of, and for, disabled people have no equivalent term to SBF in their lexicon of impairment types. It is hidden because medical authorities on impairment and disability only acknowledge fatigue in relation to cardiorespiratory disease. Lastly, it is hidden because, unlike with other impairment groups, there are no organisations representing and advocating for people with SBF difficulties broader than disease specific organisations.

The consequences of the misunderstandings, under-reporting and lack of accounting for fatigue and stamina issues are far reaching. They are deeply intertwined with the oppression we face as a group of disabled people.

Chapter Two - Chronic illness and ableism

In this chapter we look at participants' feelings about, and experiences of, identifying as a disabled person. These accounts reveal a form of oppression shared by many people with chronic illness. We explore how this experience of oppression fits into the social model framework of 'barriers' to participation, as well as more recent ideas around ableism. Finally, we discuss how participants responded to the social model of disability as a way of thinking about their circumstances.

Focus group participants evoked a deep paradox in their situation. While energy limitation and fatigue were the most 'disabling' aspect of their health condition, it was the thing that least conferred the status of 'disability' in the eyes of others. When discussing whether or not participants considered themselves to be disabled, it emerged that access to the social status of disabled person is not only socially constructed but powerfully controlled, even policed, by society generally. Nearly all participants felt they were not 'allowed', or 'deserving' enough to identify as disabled.

They described hostile encounters when referring to themselves as disabled, using accessible facilities or claiming concessions, where their status was contested. This was partly in response to having a largely invisible form of impairment, but also because of the wide-spread perception that fatigue is not associated with disability but is, rather, a universal experience that must be overcome by personal effort and willpower. "Everyone gets tired", "you don't look disabled" and "just try harder" were the most commonly encountered attitudes reported by survey respondents.

Sometimes the hostility was subtle but pervasive expressions of disbelief of their impairment experience. Other times it took the form of direct accusations of faking, exaggerating or cheating the system to obtain unfair advantages. The potential for disbelief coloured almost every aspect of social encounters and relationships, with loved ones as well as acquaintances and figures of authority. The fear of surveillance and suspicion of 'fake' disabled people profoundly affected how our focus group participants went about their life. It resulted in activity avoidance, in non-disclosure of disability, and failure to access support, adjustments and accommodations that could facilitate inclusion and participation.

It was powerfully clear that the fundamental oppression discussed by our participants was not environmental barriers but negative attitudes, essentially based on the attitude that fatigue is not a disability. We therefore suggest that much of the oppression reported by people with chronic illness takes the form of invalidation and disbelief of their impairment.

Our focus group research found that, although incidences of disbelief and hostility were frequently mentioned, they were rarely framed as structural barriers. Instead they were expressed as personal feelings, e.g. "feeling like a fraud". This suggests that oppression of people with chronic illness is strongly internalised. It also appears to result in shocking levels of emotional isolation: over three quarters of survey respondents agreed that they felt isolated by people's lack of understanding of how their health condition affects them.

Participants who did, over time, learn to challenge this oppression all agreed that identifying as disabled was liberating. People with chronic illness would therefore be likely to benefit from peer support and encouragement to challenge internalised oppression.

Disbelief and invalidation form disabling barriers to living as fully as possible with chronic illness. We suggest that developing a social model of chronic illness means understanding this oppression as a form of ableism. This is challenging and involves turning accepted ideas about ableism inside out. For example, in relation to disability discrimination, people with chronic illness experience hostile treatment on the basis of a denial of their disability, rather than directly because of it.

We begin, therefore, to interrogate and expand understandings of ableism so that they include the forms of oppression experienced by people with chronic illness.

Chapter Three – Towards advocacy

In this chapter we consider how to take action to challenge our oppression as a hidden impairment group. We consider strategies for mobilising a movement based on our identity as an impairment group, so that we can influence decisions made about our lives. We explore what are the most pressing social and political issues we need to address as an impairment group.

Our participants strongly expressed the desire to come together beyond the focus group period to have their voice heard as a constituency broader than their diagnoses. They felt that government departments do not acknowledge the existence of chronic illness as a type of disability, and most of them felt that existing organisations of, and for, disabled people did not adequately give voice to their experiences or represent their needs.

Language is an important aspect of the gap in representation and self-advocacy for people with chronic illness. Many participants felt that ‘fatigue’ is not an adequate term. Survey respondents also confirmed that neither the term ‘long-term health conditions’ nor the concept of ‘fluctuating conditions’ adequately describes their impairment experience and its impact to policy makers. Most participants agreed that a more effective framework for self-definition and self-identity is crucial if people with chronic illness are to have their voice heard.

Our research suggests that the terms ‘energy limiting chronic illness’ (ELCI) and ‘energy impairment’ are broadly acceptable within the chronic illness community as descriptions for the lived experience of their condition. We accept that not everyone with chronic illness experiences significant energy limitation, and that these terms cannot capture every individual constellation of symptoms. However, given that impairment of stamina and fatigue is so common among disabled people, we stand a much greater chance of having our voice heard and our needs met if we adopt a language that clearly conveys this experience.

Oppressive attitudes towards people with ELCI were most acutely felt by survey respondents when interacting with both the social security system and the healthcare system. Both of these areas were policy priorities for people with ELCI, rating much more highly than other policy areas affecting disabled people such as employment or social care policy.

Conclusions

What did we learn from exploring chronic illness through a social model of disability?

Both our focus group discussions and survey responses demonstrate that socially-created barriers are a major issue for people with ELCI in terms of social security and healthcare. While survey respondents wished for better medical treatment above all else, they also overwhelmingly agreed that their lives would be better if there were greater understanding and acceptance of chronic illness, and if society believed and respected people with chronic illness. Therefore, in some ways, we believe that the medical vs social model of disability for people with ELCI is a false and unhelpful dichotomy, not least because medical research and treatment is strongly influenced and shaped by social and political interests.

The CIIP has provided a way for incorporating ELCI into the social model of disability, including the impact of disbelief and denial as an attitudinal barrier experienced by people with ELCI. The social model helps us understand that our feelings of undeservingness, of shame, of feeling like a fraud, come not from our own flaws or weaknesses but from deeply negative social attitudes around disability. It helps us to realise the extent to which we internalise these attitudes in ways that further disable us.

Participants welcomed the impairment/disability binary as a tool for thinking about socially-produced disadvantage. But the idea that disability is located entirely outside the body was strongly resisted. The social model provides the chronic illness community with a transformative understanding of our experience, and a way of thinking that supports collective action but it should not form a straitjacket for language and thought.

Lastly, we conclude that paying attention to experiences of chronic illness is not in conflict with the emancipatory aims of the social model of disability. Talking about our illness or impairment is crucial to challenging powerful knowledge systems and validating our marginalised experience. Affirming our embodied knowledge is part and parcel of resisting our oppression. There can be no emancipatory framework for ELCI unless we allow discussion of illness and impairment into the frame.

We were overawed by the sheer numbers of people who took part in, or engaged with, the CIIP. We conclude that the CIIP addressed a gap in the landscape of representation for disabled people with chronic illness in the UK. This research has provided us with a framework, in the concepts of ELCI and energy impairment, to build a platform for more effective advocacy alongside and within the DPM. We must now find a way to deepen this dialogue and continue this work.

Key Findings

1. Fatigue and energy limitation were the most debilitating features of chronic illness, followed by pain, for focus group participants and for 43% of survey respondents. The latter reported significant restriction with physical activity (walking 200m) as well as cognitive function (using a computer).
2. The most common impairment type among survey respondents, at 73%, was 'stamina/ breathing/ fatigue' (SBF). Respondents reporting impairment of SBF were spread across multiple categories of disease type, the largest being nervous system diseases, and musculoskeletal and connective tissue diseases.
3. People with chronic illness experience many of the same disabling barriers as people with other forms of impairments. However, the main form of oppression reported by participants was invalidation of their experiences of impairment.
4. More than 80% of respondents felt that people think "everyone gets tired". Participants experienced this as a denial and disbelief of their experience of impairment and disability.
5. 66% of respondents felt that they risk hostility if they identify as disabled. Participants described a range of responses, from implied disbelief to direct accusations of faking or cheating.
6. About a half of survey respondents felt that legal obligations to make adjustments for disabled people do not apply to them. When they did disclose impairment, participants often found that systems of disability support are not designed for their impairment experience.
7. Half of respondents said "I feel like an imposter", suggesting that invalidation is often internalised. Focus group participants spoke of distress and self-doubt which sometimes compelled them to behave in ways that reinforced their oppression.
8. 85% of respondents reported feeling isolated by society's failure to understand the impact of their condition. This emotional isolation clearly compounds the isolation that results from reduced face to face contact with ELCI.
9. When polled over possible alternative language for self-advocacy, the term 'energy impairment' was accepted by 72%, and "sometimes" by a further 15% as an alternative to the term 'fatigue'. The term "energy limiting chronic illness" (ELCI) as a descriptive label of their identity as disabled people was strongly preferred over the existing categories of 'long term health condition' and 'fluctuating condition'.
10. Respondents' policy priorities were healthcare and social security, with Personal Independence Payments (PIP) a particularly strong priority. Interactions with DWP staff and healthcare professionals were perceived to be the main source of oppressive attitudes towards people with chronic illness.
11. Issues of independent living such as social care provision, and choice and control over support, are near the bottom in terms of policy priorities, notwithstanding strong evidence of need for care and support in daily living.
12. Nearly two-thirds of survey respondents said that improved medical treatment was the main thing that could significantly improve their quality of life. At the same time, more than four in five agreed that better understanding of and accounting for chronic illness would significantly improve their quality of life.

Key Recommendations

Our manifesto for equality and inclusion for chronic illness sets out our full programme of demands. Some of our important recommendations to key bodies are listed here:

World Health Organisation (WHO) and other health authorities should:

1. Review the International Classification of Functioning, Disability and Health, considering the reality that problems of fatigue and stamina apply much more widely than just the domain of cardio-respiratory medicine.

The UK Government and other public bodies should:

2. Recognise people living with impairment of stamina/breathing/fatigue as a discrete impairment group. Disability support systems should be expanded to account for our specific needs and experiences.
3. Incorporate an understanding of the lived experience of ELCI and its impact on function into all disability assessment systems for government programmes of disability support, benefits and concessions.
4. Devote specific funding for biomedical (*not* biopsychosocial) research into pathological fatigue, including its impact on cognitive function, given its centrality in chronic illness experience. The development of biomarkers for fatigue states is crucial for demonstrating eligibility for social support.
5. Government Statistical Services should review the language for the category of 'stamina, breathing, fatigue' for use in social surveys on disability, and consider replacing it with 'energy impairment' reflecting participants' preferred language for self-identity.

The disability sector (organisations of, and for disabled people) should:

6. Engage with the knowledge and experiences of people with chronic illness, and support our language of self-identification.
7. Include and represent people with ELCI and energy impairment in education and training on access and inclusion.
8. Challenge ableist attitudes and practices in all their forms and manifestations, including invalidation and disbelief.

Foundations, funders and charitable organisations should:

9. Support the establishment and sustainability of a user-led organisation for people with energy limiting chronic illness (ELCI). Its aims and purposes would be:
 - ◆ Capturing our lived experience and knowledge, and amplifying our voice;
 - ◆ Involving us in the design of policies and services;
 - ◆ Encouraging take up of the terms ELCI and 'energy impairment' as strategies for self-advocacy in claiming our rights as disabled people;
 - ◆ The development of information and training on ELCI and energy impairment to increase our access, inclusion and entitlements as disabled people.

INTRODUCTION

The Chronic Illness Inclusion Project (CIIP) ran from April 2017 to December 2019. To our knowledge, it was the first piece of research in the UK by, and for, disabled people to comprehensively address the experience of chronic illness as a distinct form of impairment within the framework of the Disabled People's Movement (DPM).

The purpose of our research has been to produce a manifesto for equality and inclusion and to lay the foundations for a sustainable self-advocacy movement for the chronic illness community. Our activities have included community engagement and stakeholder engagement as well as research (see Appendix 1 for more detail on project activities and our manifesto).

To this end, we explored chronic illness through a social model of disability. We invited our participants to distinguish between how their body or health condition disables them, and how external factors like environmental barriers and social attitudes disable them. This helped us to identify the social and political changes we want to see.

A key achievement of the CIIP has been to develop a methodology for making focus group participation accessible to people with severely debilitating chronic illness who struggle to, or cannot, leave their homes. Our online focus group was complemented by a large-scale survey, enabling us to capture both the breadth and depth of knowledge and experience in the chronic illness community. We heard from over 2,000 people in total. This report details the extensive findings of our research.

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What is the chronic illness community?

While face to face support groups have long existed, more recently the internet and social media have fostered networks and communities for people with chronic pain and chronic illness who are unable to meet face-to-face (Gonzalez-Polledo, 2016; Ytre-arne, 2016). Some of these networks are disease-specific, and focus on advocacy for better medical research and treatment. However, cutting across them are networks that acknowledge a common predicament between diagnostic labels, especially when diseases are rare, hard to diagnose, or medically contested. They coalesce using certain labels of identity, most often #chronicillness and #spoonie.

When we asked our participants about the basis of the chronic illness community, and what they have in common with others, they mentioned leading a particular way of life. Their sense of difference involved both 'being very limited in day to day life' and 'feeling like a fraud'.

One participant expressed it thus:

we are different...

we have to always have survival in mind.

we have to know what the consequences of our every day actions will be and we have to plan for them in advance.

we have to know when enough is enough, before it is enough.

then we have to do the normal stuff that others have to do.

then people ask what you've been doing all day.

they tell you things will improve.

then if you have a good day you feel like a fraud.

tiring but it doesn't need to be.

we shouldn't have to struggle like we do and worry if money will be taken away and that will lead to losing our houses.

we shouldn't have to be assessed and reassessed for the small benefits we get. [...]

we will never get 'better' and it should be obvious to anyone that we are special.

we are travellers in these broken vehicles that cannot be fixed...

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Our focus group participants valued social media communities for the peer support; the sharing of information, especially when it helped them in getting a medical diagnosis and treatment; a shared sense of humour, especially 'dark' humour; and a sense of belonging to 'something bigger' than their own restricted world.

However, this community largely exists online in 'grassroots' networks and has no formal organisation. The knowledge we share between ourselves doesn't reach the people who make decisions about our lives. We wanted to explore why this is and how we can change it.

Chronic illness and the social model of disability

The CIIP is not concerned with researching treatment and cure for particular diseases, or with individualised solutions for coping better with suffering. Many patient representative organisations do this important work already. Rather, our research explored how our lives could be improved through social and political change. In this sense, we are exploring chronic illness through a social model of disability.

Since its articulation by Union of the Physically Impaired Against Segregation (UPIAS) in 1976, the social model of disability has encouraged new, transformative, ways of thinking about how people with impairments, or perceived impairments, are prevented from fully participating in society. The social model rests upon a distinction between 'impairment', defined as 'Lacking part or all of a limb, or having a defective limb or mechanism of the body' and disability, 'the disadvantage of restriction of activity caused by a contemporary social organisation which [...] excludes them from participation in the mainstream of social activities' (UPIAS, 1976 in Barnes, 2012).

Thus, according to the social model ‘Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from society. Disabled people are therefore an oppressed group’ (UPIAS, 1976: 4).

Some people have said that chronic illness and the social model of disability are conceptually incompatible. There are those in the DPM who think that people with chronic illness focus too much on impairment, i.e. on restriction, suffering and the pursuit of medical intervention. They see this as unenlightened at best; at worst a betrayal of the social model of disability. On the other hand, there are many in the chronic illness community who think the social model does not apply to them because addressing external barriers and discriminatory attitudes doesn’t mitigate the impact of chronic illness enough to enable social participation. In both views, chronic illness and disability are different states and shouldn’t be confused.

We wanted to explore this tension further. The social model of disability was mainly developed by people with physical and sensory impairments. However, in recent years, people with learning difficulties, mental health service users and people with dementia have all turned to the social model of disability to develop and promote an understanding of their rights (Beresford, Perring et al, 2016; Milligan & Thomas, 2016). We aimed to find out whether, and how, developing a social model of chronic illness could advance our rights as disabled people.

We also hoped that developing a social model of chronic illness would help us to move closer to and build solidarity with the DPM in the UK.

Therefore, we invited our participants to explore the distinction between impairment and disability as a framework for focusing on social and political change. Our exploration of ‘impairment’ focused on the lived experience of disease and disability, rather than medical or scientific accounts of what is wrong with our bodies or minds. This is sometimes called phenomenological knowledge, or embodied knowledge. Our exploration of ‘disability’ focused on the way society oppresses people with impairments, by imposing barriers and other unnecessary restriction to wellbeing and participation in society.

Because of the contested meanings of the word ‘disability’, we refer to socially-produced disability as ‘ableism’.

Theoretical background

The theoretical context of our project is the relationship between the chronic illness community and the DPM in the UK.

With a few exceptions there has been surprisingly little research from within UK-based disability scholarship on ‘chronic illness’ as a distinctive experience (Bê, 2016; Wendell, 1996). There is a growing body of work from the US and Canada, particularly incorporating a relatively new approach to disability, ‘crip theory’, and there are studies on specific conditions, such as Hepatitis B ((Patsavas, 2014; Sheppard, 2018; Mack & Paylor, 2017).

In fact the concept of ‘chronic illness’ was suppressed with the establishment of critical Disability Studies and the founding of the DPM in the UK in the 1990s (Hale, 2018). Chronic illness was replaced with, and encompassed by, the term ‘impairment.’ Impairment was intended as a value-neutral description, shedding the stigmatised

associations between illness and social deviance found in the influential theories of sociologist Talcott Parsons on the ‘Sick Role’ (Oliver, 2016).

At the same time, under the social model of disability that underpinned these movements, the inquiry into impairment was side-lined by the focus on disability, understood as the social oppression of people with perceived impairments:

The social model is a deliberate attempt to shift attention away from the functional limitations of individuals with impairments onto the problems caused by disabling environments, barriers and cultures.

Barnes, 2012

While this strategy has been emancipating for many disabled people, it has been of less benefit to people with chronic illness, whose distinct experiences of disability and identity as disabled people has been erased from the lexicon of disability activism. The emancipation of people with chronic illness as a community demands that we interrogate the suppression of chronic illness as a distinct experience or identity, as well as the suppression of discussion about impairment within the UK DPM.

There are several strands of argument against exploring chronic illness through the social model of disability.

A minority of disability scholars have expressed the view that pain and chronic illness are not really impairments because they are experiences shared by non-disabled people (Swain & French, 2000). A more common view among disability scholars and activists is that embodied experience of impairment may well be distressing and restricting, but that they should not be brought into public discourse on disability because this reinforces the oppressive ‘personal tragedy’ model of disability and detracts from the focus on removing societal barriers and advancing disability rights (Oliver, 2016). According to this logic, people with chronic illness are not disabled people in the sense understood by the DPM.

From within the chronic illness community itself, it has been argued that illness (or ‘sickness’) and disability should be kept conceptually separate. This argument surfaced around 2012, in response to emerging anti-austerity campaigns by people with chronic illness, such as the Spartacus Network. The phrase ‘sick and disabled’ was coined to draw attention to the different needs and capabilities of people with chronic illness compared to other impairment groups, and because it was felt that the narrative of the Disability Rights community in relation to work did not represent the experience of people with chronic illness (Marsh, 2011; Young, 2012).

There are several negative consequences of these arguments for people with chronic illness, as some scholars and commentators have noted. Feminist critiques noted that the suppression of public expressions of suffering and distress is itself oppressive, and called for the social model to include private as well as public aspects of disability (Morris, 1991; Crow, 1996). Crow points out that if we don’t articulate our experience of impairment, we cannot formulate our needs and demand that society responds to them (Crow, 1996). This is especially true when impairment is not immediately visible or not well understood. De Wolfe notes that separating illness from disability may benefit some disabled people while further marginalising others:

attempts to specify a distinction between disability and illness simply shift the boundaries of social and conceptual exclusion. Chronically sick people remain stigmatised, with their strengths unrecognised and measures to improve their lives unformulated.”

De Wolf, 2002

Perhaps most importantly, the notion that impairment is a value-neutral concept implies that biomedical descriptions and classifications of disease and impairment are neutral and objective descriptions of reality. Wendell strongly contests this position from a philosophical standpoint (Wendell, 1996; 2016). Its consequences are that lived experience of illness and impairment that diverges from medical knowledge about the body and disease remains subjugated knowledge, and people with undiagnosed or contested illnesses remain disenfranchised as knowers and marginalised within society (Bê, 2019; Wendell, 1996).

Lastly, suppressing discussion of impairment implies that all disabled people, regardless of the nature of their impairment, share the same experiences of disablement, or ableism. This means ableism is universalised, not only with regard to ethnicity, class and gender but with regard to impairment type (Hale, 2018). As a result, different forms and experiences of ableism are not articulated within the DPM.

The CIIP reclaims the term ‘chronic illness’ as marker of self-identity as disabled people (Hale, 2018). Our research focused on impairment as well as disability, because we believe that the relationship between impairment and disability is not universal to all impairment groups, but should be the subject of investigation (Thomas, 2012). We also believe that a discipline which privileges disabled people’s knowledge and experience should pay attention to their views and perspectives on impairment, rather than accepting medical claims about the nature and meaning of impairment (Shakespeare, 2014).

Thus, the CIIP seeks to understand chronic illness as a ‘category of impairment’ with the aim of embedding the experience of chronic illness within the lexicon of disability as a concept that is more reliably defined, understood and legislatively supported (Bê, 2016; Price, Walker, & Booth, 2019).

Methodology

In order to elicit both the depth and the breadth of knowledge within the chronic illness community, we used a combination of qualitative and quantitative methodologies. We began with an online research forum, which we refer to as a ‘focus group’. Then we developed a survey to test the knowledge and experiences shared in the focus group among a much larger sample.

Our research was designed to be as inclusive and accessible as possible to people who would be unable to attend, or have difficulty in attending, meetings in person due to energy limitation.

The CIIP involved three researchers, Catherine Hale, Jenny Lyus and Stef Benstead, all of whom live with chronic illness. Jenny Lyus had to withdraw due to deterioration in health. Analysis of survey findings was carried out by Evan Odell, Stef Benstead and Victoria Clutton, as well as Catherine Hale. We were supported by a Project Advisory Group of 14 people in total, all of whom are disabled and living with chronic illness.

Research questions

Although the questions we asked in the survey did not overlap exactly with those in the focus group, these were the overarching questions of our research:

- What, if anything, unites us as a community? What do we share beyond our diagnostic labels? Using a social model of disability approach, we tried to capture lived experiences of impairment, as well as lived experiences of ableism.

- How can we ensure our voice is heard and our rights are respected? What prevents us from having our voice heard? Could we reframe our experiences to communicate more effectively to people outside the community, especially decision makers?
- How helpful is the social model of disability in improving our lives?
- What are our priorities for social and political change?

Focus Group

Our qualitative research phase involved a specially tailored online research forum for approximately 20 people, lasting two months and allowing in-depth exploratory discussion. We refer to this as an ‘online focus group’.

An important part of our ethical considerations for doing emancipatory disability research was to interrogate, and take steps to address our own bias as researchers with lived experience of chronic illness. Both researchers (Lyu and Hale) during the period of research design lived with Myalgic Encephalomyelitis (ME) and were active in online activist networks for people with ME. In order to ensure representation from other sectors of the chronic illness community, we actively selected focus group participants with a broad range of health conditions and diagnoses, as well as seeking to balance other demographic characteristics. See Appendix 2 for more detail on our sampling method.

Our use of online software for qualitative research has important implications for researchers aiming for pan-impairment research (see Olsen, 2019).

Our choice of medium for the focus group reflected our prior knowledge and experience of the access issues faced by people with energy limiting chronic illness. We knew that fluctuating symptoms and the energy drain of travelling to a venue, sitting upright and sustaining concentration for a two-hour period makes participation in traditional focus groups difficult or impossible for many people with chronic illness. We, therefore, chose an internet-mediated research format that enabled participation from home.

Our choice of platform for the online focus group was also determined by the ethical considerations of conducting research among a group vulnerable to mental distress due to social isolation. We wanted to guarantee privacy and anonymity to participants who may have belonged to the same social media networks and communities outside of the focus group. For this reason, we used specialist focus group software rather than a social media platform such as Facebook for qualitative data collection. We selected focus group software designed for commercial market research and adapted it for the purposes of social research.

The focus group software offered three advantages: 1) Participants were encouraged to use a pseudonym unrelated to their social media profile, giving them greater privacy and anonymity. 2) The software was designed to elicit ‘unbiased’ responses to questions. That is to say, participants had to post their response to a question before being allowed to view and engage with other participants’ responses. 3) Responses were text-based and were permitted at any time in the following two weeks after a topic was posted. In this way, we were able to accommodate fluctuating, energy limiting conditions.

Over a period of eight weeks, a new topic with between one and three questions was posted to the research forum every two weeks. (See Appendix 4 for the schedule of topics and questions). Three researchers were active during the focus group period: two moderators and one observer who analysed the comments in real-time to provide feedback to the moderators.

Participation was unexpectedly intensive from many participants, and our questions yielded unanticipated volume of data. The focus group generated over 38,000 words of discussion. We had initially planned for the focus group to last for six months and cover additional topics around social inclusion and chronic illness. However, after eight weeks both participants and researchers could no longer sustain the focus group activity, so we redrew the parameters of our research agenda.

All focus group participants met the threshold for disability under Equality Act 2010 provisions.

Gender: 14 female, 5 male, 1 transgender male

Age: 2 were aged 18-24, 11 were aged 25-39, 7 were aged 40-65 and 1 was over 65

Self-reported activity restriction: 18 were restricted 'a lot', 1 was restricted 'a little'

Impairment rating using Bell fatigue scale (see Appendix 3): 2 at 10%, 2 at 20%, 7 at 30%, 3 at 40%, 3 at 50% and 2 at 60%

Multi-morbidity was a striking feature of all applicants to the focus group. All mental health conditions reported were comorbid with one or more physical health conditions. In their own words, these were the health conditions and diagnoses listed by the 25 focus group participants we selected:

Anaemia, ankylosing spondylitis, Asperger's, asthma, anxiety, BPD, cancer, chronic fatigue, chronic liver disease, COPD, congenital vertical talus, CSF leak, cystic fibrosis, degenerative disc disease, depression, displaced L4/L5 vertebrae, dyspraxia, Ehlers-Danlos Syndrome, epilepsy, erectile dysfunction, female problems, FND, Hard of hearing, HIV, hypermobility syndrome, idiopathic angioedema, lower back pain, Mast Cell Activation Syndrome, MBL deficiency, ME, migraine, nerve root impingement, neurochemical disorder, OCD, osteoarthritis, osteoporosis, Parkinson's, peripheral neuropathy, POTS, poly-cystic ovaries, PTSD, prolapsed discs, pulmonary hypertension, pulmonary stenosis, rheumatoid arthritis, sarcoidosis, scoliosis, seizure (dissociative/non-epileptic), SIBO, Sicca syndrome, sleep apnoea, systemic lupus, thyroid, Type 2 diabetes.

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Of the 25 participants recruited, 19 were active throughout the focus group period.

Survey

The purpose of our survey was to investigate whether the experiences and opinions expressed in our qualitative research among 20 participants were shared by a larger sample of people living with chronic illness.

The survey called for people with chronic illness to share their experiences. It was open to anyone over 18 who met the Equality Act (2010) provisions for disability. Recruitment

of survey respondents was via our mailing list as well as via social media platforms (Twitter and Facebook). The survey was open from 27th July to 31st October 2018.

Respondents also actively engaged in sharing and promoting the survey in their own online networks and communities. Respondents urged others to take the survey because, they said, it asked questions that they are not normally asked about their lives and experiences. We tried to reach as many disease communities as possible by asking our mailing list subscribers to be ‘ambassadors’ for the research by sharing the survey among their disease-specific networks if they had a relatively rare health condition. The survey was also disseminated by Disability Rights UK, yielding 13% of total responses.

Thanks to this ‘snowballing’ effect and ‘viral’ form of online dissemination, we achieved over 2,000 responses in approximately three months.

87% of our respondents were based within the UK, with the remainder coming from outside the UK.

Ethics

The Disability Research on Independent Living and Learning (DRILL) programme which funded the CIIP was set up to support research that is conducted with, and for, disabled people. The CIIP aims to follow the principles of emancipatory disability research and service user-led research (Oliver, 2002; Barnes & Mercer 1997; Vernon 1997; Oliver 1997) Faulkner 2005; Beresford & Wallcraft 1997).

The starting point for our research agenda was our own lived experience of chronic illness and our participation in social media networks of people with chronic illness, especially on Twitter and Facebook, over several years prior to the project.

As disabled researchers, we determined the research agenda. We position ourselves as equal in knowledge and experience of chronic illness to our research participants. We challenge the knowledge produced by non-disabled professionals about people with chronic illness, whether in the fields of social policy or healthcare. Our research was conducted not as an end in itself, but in the service of social action and change.

The DRILL ethics committee provided ethical oversight and approval for this project. Our Ethics Review considered the ethical challenges of our research from the perspective of a) internet-mediated research (Im & Chee, 2006, 2012) and b) the characteristics of our target participants and their specific ‘vulnerability’ to harm. See the Methodology section for detail on the measures taken to address these risks.

1. A hidden impairment group

This chapter discusses a) what it is like to live with chronic illness, and b) who we mean by the ‘chronic illness community’. It presents first-hand accounts of the embodied experience of living with chronic illness from our focus group participants, followed by our quantitative data on impairment type, disability status and medical diagnoses and classification from survey respondents. We conclude with a discussion of why we think people with chronic illness are a hidden impairment group.

Key Findings

1. Fatigue and energy limitation were the most debilitating features of chronic illness, followed by pain, for focus group participants and for 43% of survey respondents.
2. The latter reported significant restriction with physical activity (walking 200m) as well as cognitive function (using a computer).
3. Pathological fatigue is a global body-mind experience that is radically different from every-day “tiredness”, and is difficult to convey through language.
4. Managing pathological fatigue keeps people tied to their homes and results in significant loss of face-to-face social contact.
5. In terms of demographic characteristics, respondents to our survey were overwhelmingly women, aged 40–65, who reported significant activity restriction.
6. Almost 9 out of 10 said their impairment was normally invisible.
7. Most of them reported multi-morbidity (more than one health condition) and more than 2 in 5 respondents had a co-existing mental health condition.
8. The most common impairment type among survey respondents, at 73%, was “stamina/ breathing/ fatigue” (SBF).
9. Respondents reporting impairment of SBF were spread across multiple categories of disease type, the largest being nervous system diseases, and musculoskeletal and connective tissue diseases.

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Lived experience of impairment with chronic illness

“Fatigue is the worst”: the most debilitating feature of chronic illness

Focus group participants were very keen to express and describe their lived experience of chronic illness from the outset of the research process. This topic arose spontaneously,

outside of our schedule of questions, and attracted more discussion and interaction than our scheduled topics.

All but two participants agreed among each other that fatigue was the most restricting aspect of their health conditions. One participant said pain was slightly worse than fatigue; another said that the unpredictability of their symptoms was the most debilitating aspect of their condition, due to their inability to make plans.

This was the case despite wide ranging diagnostic labels and health conditions (see Appendix 5). A male participant with refractory sarcoidosis commented:

The stiff joints, the blurred vision, the headaches, nausea and vertigo, all of that I can tolerate but it's the fatigue that keeps me housebound and out of work. No matter how much rest I get or how hard I will myself to try, I simply have no energy.

Among survey respondents, 43% said 'Fatigue' or 'limited energy' was the most restricting feature of their health condition(s) 27% selected 'pain'.

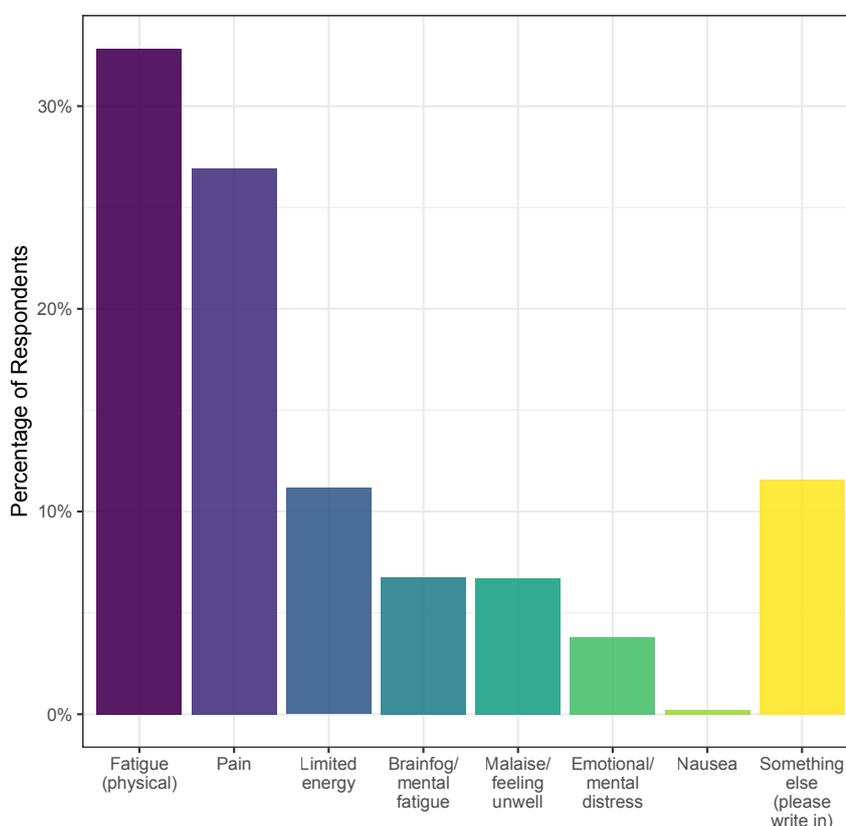


FIGURE 1. Most restricting feature of health condition

Just over one in 10 respondents selected 'something else' than the symptoms listed as the most debilitating aspect of their health condition, of which 222 responded in the free text box. Out of these 'something else' responses, almost half said it was not possible to select one symptom or feature because it was the combination of two or more features that caused activity restriction. The combination of physical and mental fatigue was most frequently mentioned. The relatively low score for brainfog/mental fatigue (7%) should therefore be interpreted in the context of the impossibility of disentangling physical

and mental fatigue. The second most frequently mentioned combination was pain and emotional distress.

The most commonly mentioned symptoms or features in the ‘something else’ category (in order of frequency) were:

- ◆ Mobility: 7% (including restricted joint movement and difficulty walking)
- ◆ Breathing difficulties: 6%
- ◆ Balance, vertigo, dizziness, light-headedness: 6%
- ◆ Post-exertional malaise: 5%
- ◆ Cognitive impairment (not adequately described by brainfog/mental fatigue): 5%
- ◆ Orthostatic intolerance (including dysautonomia): 5%
- ◆ Paralysis (including muscle weakness): 4%
- ◆ Continence: 4%
- ◆ Vision: 3%

A pathological state

All focus group participants agreed that living with chronic illness entailed a radically different existence from their pre-illness state. In particular, the fatigue they experienced was completely outside the range of ‘normal’ tiredness.

Fatigue is by far my worst issue and the one that rules my life. It's not just ‘tiredness’ is it, it's a bone deep, spaced out exhaustion that makes me [sic] body feel like it's made of lead and my head feel like it's stuffed to bursting with cotton wool.

When I get tired I feel like I'm dying. If I don't give in to it then I wish I was dead. It is said with dry humour but it is exactly how I feel.

The scale of fatigue makes every day, taken-for-granted activities such as self-care impossible.

Fatigue is brutal. It's not being tired and no amount of rest helps. Even holding your head up is a chore. Simply things like having a shower can be too much. Mix with pain and it'll rob you of your personality.

A global body-mind state

Participants vividly described fatigue as a total body-mind state of impairment, which is often inseparable from pain and encompasses both physical and cognitive fatigue. Fatigue with chronic illness is experienced as an alien state of being, involving the loss of many previously taken for granted abilities, and resulting in a loss of sense of self.

When the exhaustion is really bad it's such a weird experience. I feel like there is a tiny part of my mind that still sort of functions surrounded by cotton wool in a dead body.

It is the overwhelmingness (is that a word?!) of the exhaustion that just sweeps over you. Those who know me best can see it happening.

Living with chronic illness changes the parameters of space and time, producing a radically different state of being in the world and different relationship with time:

I lose time quite a lot, or perhaps I just don't make memories when I'm very tired. I have a lot of instances of doing things when I'm not quite conscious and then having no memory of them which can be very disconcerting.

Our survey captured the extent of mobility impairment with chronic illness. Respondents were asked how often, over the past 12 months, they had had enough energy to go out on short errands in the area within 200m of their home, without using a wheelchair/mobility scooter and without needing a lot of rest afterwards.

34% of respondents were never able to walk for 200m or more without significant pain or need for rest.

18% were able to do so only occasionally.

8% were always able.

The global experience of fatigue results in notable impairment of cognitive function. Participants described difficulties with understanding, speech, memory and concentration. They explained how this affects them in day to day life.

I find that I'm terrible at budgeting when I'm exhausted. I don't remember what I've spent and how much money I have left, I forget to pay for things, and I can't think long term.

Brain fog has been one of the hardest things for me. I used to be a high-flying straight A student and now I can't even remember my own phone number... I find myself struggling to write a basic shopping list, wanting to cry because it feels so hard with my treacle-for-brains.

The cognitive dimension of fatigue causes significant activity restriction in tasks requiring sustained concentration, short term memory, communication, information processing. Our findings suggest that cognitive difficulties in chronic illness can be substantial, but entail limited duration of cognitive function rather than impairment of reasoning or intellect.

Our survey sought to measure cognitive stamina. We used hours per week of computer use as a proxy measure for mental stamina for tasks of information processing, concentration and communication.

Respondents were asked for how long, over the past 12 months, they were able to use a computer, e.g. for browsing the internet, communicating or reading.

38% of respondents were unable to use a computer for more than 15 hours a week.

10% could manage less than five hours per week.

A quarter could manage between 16 and 24 hours of computer use per week.

36% could manage more than 25 hours per week.

Physical and cognitive stamina were closely connected.

49% of respondents who could never or only occasionally walk 200 metres were unable to use a computer for more than 15 hours per week.

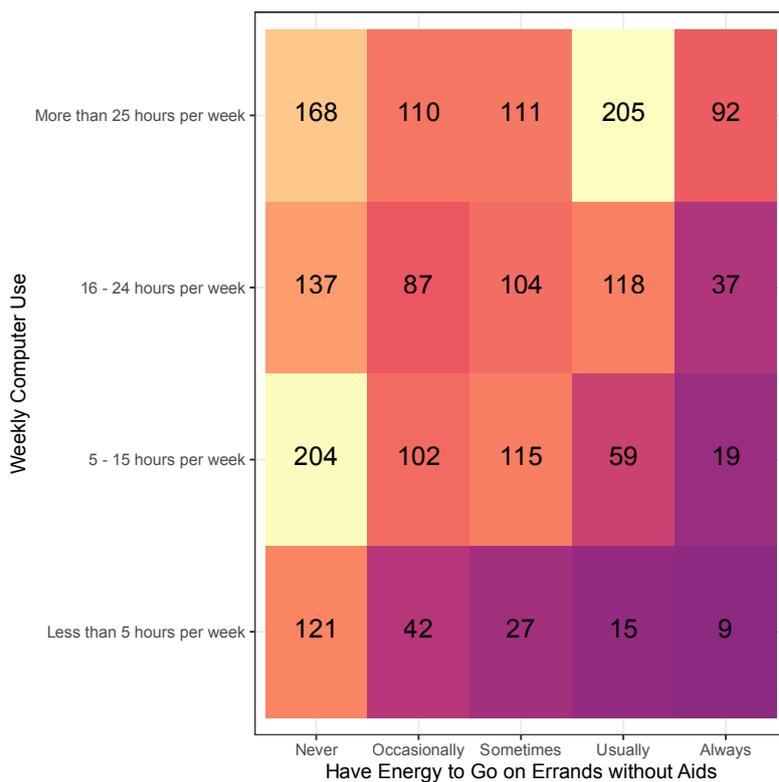


FIGURE 2. Correlation between physical and cognitive fatigue

Focus group participants noted that the term ‘fatigue’ itself fails to convey the all-pervading experience of limited energy. Even among supportive close relationships, the experience of fatigue and pain and their impact are difficult to communicate.

My partner is my rock but couldn't understand why I couldn't sleep yet was exhausted. Someone on my [online support group] put up the spoon theory. It was a eureka moment. My partner read it and he finally got it.

It took her [participant's wife] giving up the daily commute and working full time from home to really understand what I was dealing with. I'd told her but I think there was at least some part of her that thought I was exaggerating or gaslighting her somehow.

Participants put much effort into describing and proposing terms to explain their experience:

Climbing a hill with a sack of rocks I can never put down? Swimming through treacle?

Participants spoke of their impairment as “severely debilitating”, “life altering” and categorically different to everyday aches and pains and tiredness. They proposed creative descriptions and metaphors, including ‘spoon theory’, a faulty mobile phone battery and the concept of “energy resource management” to convey how the impact of the impairment permeates every activity and task previously taken for granted.

You know the times you pull out your phone to text someone, only to realise it's died and you didn't think it was even on low battery? I think that can be a somewhat broad metaphor for many chronic illnesses...The phone 'dying' can represent heightened pain, extreme fatigue, severe brainfogging, etc. And so can be applied to a wide number of illnesses...A phone without battery is unable to do any of the tasks it could before.

The rich descriptions given by focus group participants of how their day to day lives were restricted demonstrate that understanding impairment with chronic illness entails much more than a one-dimensional notion of fatigue. Most participants agreed that each small task of daily living has to be approached using a calculation of energy expenditure and the consequences of ‘overspending’ their energy allocation. Going into energy ‘debt’ means increased symptoms and further loss of stamina and function. Thus, living with chronic illness involves strategic decision making, planning and prioritising of how to spend limited energy resources in each moment of the day.

I only get to do so many tasks before brain fog sets in, before my bodily strength gives out.

The day to day management of my condition is about how to allocate my very limited resources in the best way. I don't think healthy people who don't know someone with chronic illness have any idea that's what it can be like or how many things they take for granted (like having a shower) are things we have to think about strategically and sometimes choose to do without to enable more important things.

Our survey asked about the extent of energy rationing and its impact on daily living by asking respondents how much planning and prioritising they have to do, if any, to manage fatigue, pain or limited energy.

Extremely - feeding myself and personal hygiene depend on detailed planning and prioritising of limited energy/fatigue/pain	21%
A lot - everything I do involves planning and prioritising limited energy/fatigue/pain	39%
On a daily basis I have to plan and prioritise activities to take account of limited energy/fatigue/pain	28%
I sometimes have to plan and prioritise activities to take account of limited energy/fatigue/pain	11%
None at all - I don't typically have limited energy/fatigue/pain	1%

TABLE 1. How much planning and prioritising do you have to do to manage pain, fatigue, or limited energy?

All focus group participants described themselves as having limitations in terms of being able to go out and take part in activities such as work, leisure and social life due to fatigue and energy limitation: “I can't manage work, socialising or many outings and so on with the family”. The experience of energy limitation appears to tie people to their home environment to a greater or lesser degree: “I'm effectively housebound”; “the rare occasion I'm anywhere other than at home.”

Being tied to their homes was not expressed as a sense of being trapped at home by inaccessible housing, transport or built environment. Rather it was expressed as a need to remain at home in order to manage their energy levels because the cognitive, sensory as well as physical challenges of going out depletes energy reserves.

Almost all participants mentioned having lost friendships or social connections from work and experiencing isolation as a result of being tied to their home.

Demographics of chronic illness

1. Respondents to our survey were overwhelmingly women aged 40–65 who reported significant activity restriction as a result of their health condition.
2. Almost 9 out of 10 said their impairment was normally invisible.
3. Most of them reported multi-morbidity (more than one health conditions) and more than two in five respondents had a co-existing mental health condition.
4. The most common impairment type among survey respondents, at 73%, was “stamina/ breathing/ fatigue” (SBF).
5. Respondents reporting impairment of SBF were spread across multiple categories of disease type, the largest being nervous system diseases, and musculoskeletal and connective tissue diseases.

2,344 people responded to our online survey. The size of this sample, along with the diversity of health conditions and balance of age, permit us to draw some interesting preliminary conclusions about disabled working age adults who have chronic illness.

62% of respondents were in the 40 to 65 age range.

83% of respondents were female and 13% were as male. The remainder reported 'Other' (3%), 'transgender male' (0.37%), 'Transgender female' (0.42%) or preferred not to say (0.5%).

77% of respondents were heterosexual.

99% of respondents met the Equality Act (2010) criteria for disability. 78% reported 'a lot' of activity restriction, compared with 21% reporting 'a little' activity restriction.

88% said their impairment or health condition was normally invisible, of which 32% said their impairment was only made visible by the use of a mobility aid or medical equipment.

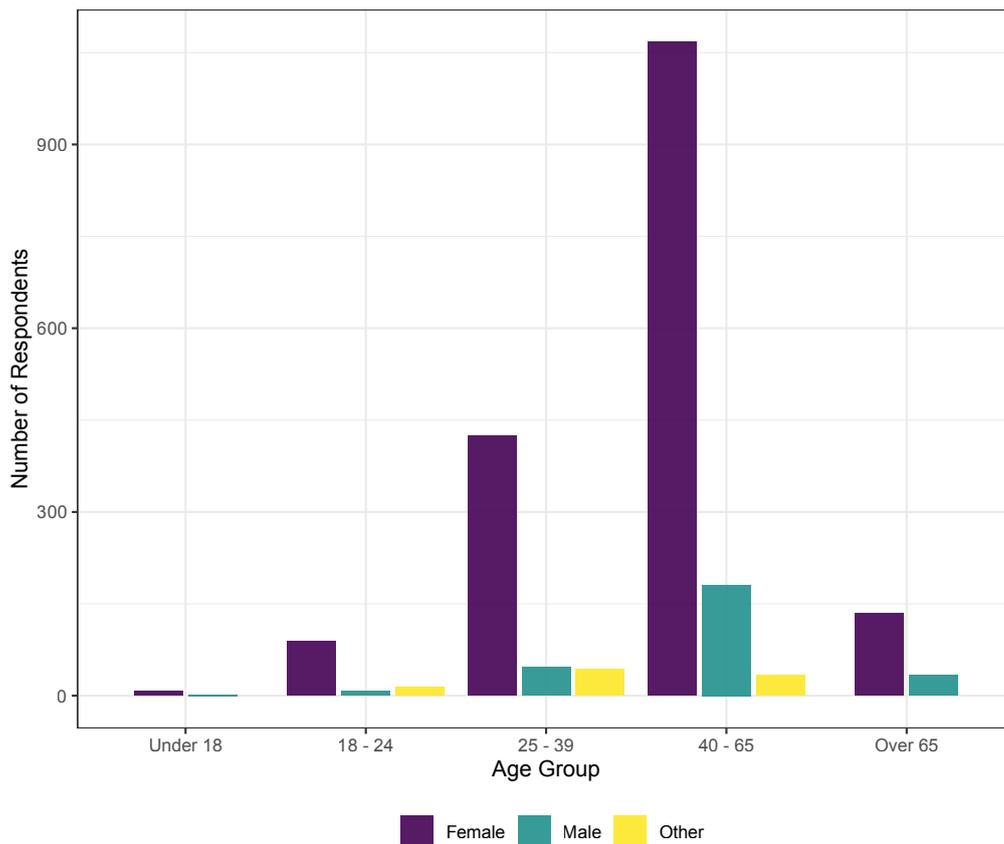


FIGURE 3. Respondents by age and gender

The reasons for the stark sex imbalance merit further investigation. One explanation could be the much higher prevalence of autoimmune conditions among females (Fairweather & Rose, 2004). A large proportion of conditions reported by respondents (see below) can be characterised as autoimmune conditions. Another possible explanation is that the vast majority of active members of online chronic illness communities, across blogging, Facebook and Twitter, are female. It is possible that males living with chronic illness are less drawn to peer support, information sharing and self-expression through the medium of the Internet, and therefore are far less active and represented in the online chronic illness community.

Respondents were presented with a list of impairment types used by the DRILL programme for evaluation purposes. They could select more than one category. An additional category of ‘stamina/breathing/fatigue’ (SBF), recommended by the Office for National Statistics, was added to the choices as the researchers’ experience suggested that none of the DRILL categories were particularly associated with chronic illness.

73% of respondents who reported a long-term health condition said they had difficulties with ‘stamina, breathing or fatigue’.

More than two in five reported a mental health condition.

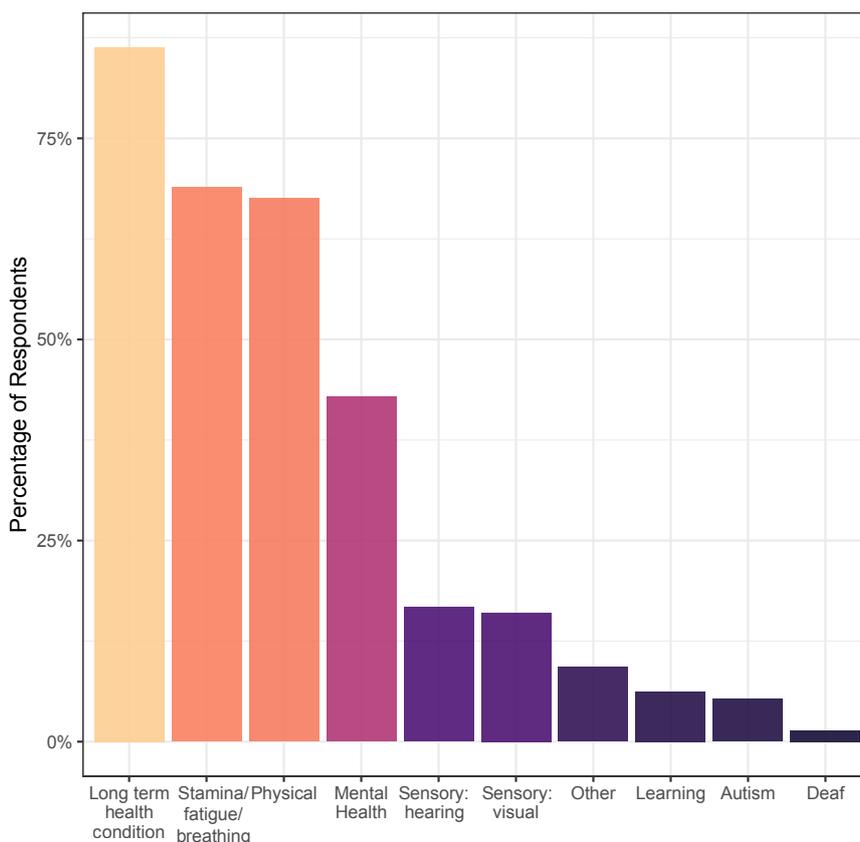


FIGURE 4. Impairment type

A striking picture of both multimorbidity (having more than one health condition) and mental health comorbidity emerges from the data on self-reported conditions.

Respondents listed an average of 3.5 conditions each. Excluding mental health, the most commonly reported conditions when similar conditions are grouped together are ME/CFS, Fibromyalgia, Arthritis, Asthma, Irritable Bowel Syndrome, Hypothyroidism, Osteoarthritis, Migraines, Postural Tachycardia Syndrome and Diabetes.

There was a high incidence of conditions that are contested or not formally recognized within the NHS, such as Mast Cell Activation Syndrome and Chronic Lyme Disease.

Depression and anxiety were within the top five most frequently reported conditions. However, it is important to note that only 0.9% of respondents reported only mental health conditions, so depression and anxiety were almost all comorbid with physical health conditions.

An indication of the most frequently reported physical health conditions is given in Figure 5 where the font size increases with frequency. See Appendix 5 for an explanation of the analysis of health conditions and further analysis of the correlations between commonly reported conditions.

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FIGURE 5. Conditions with a frequency of 30 or more (excluding mental health conditions)

We classified each reported condition according to the broad 'chapters' of the International Classification of Diseases (ICD10) by WHO. The most prevalent disease chapters were, in order: nervous system diseases; musculoskeletal system and connective tissue diseases; mental, behavioral and neurodevelopmental disorders; endocrine, nutritional and metabolic diseases; digestive system diseases; circulatory system diseases and respiratory system diseases (see Figure 6).

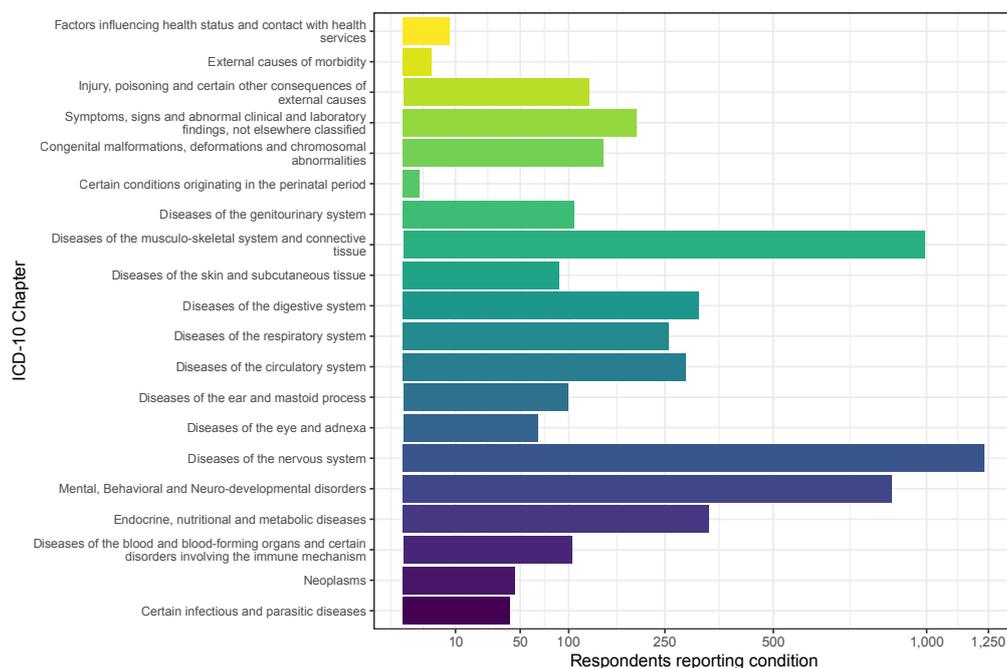


FIGURE 6. Classification of reported health conditions in survey

Discussion

Our survey confirmed the reports in our focus group: that fatigue and energy limitation are the most restrictive aspect of living with chronic illness. The most common impairment type among survey respondents was ‘stamina, breathing, fatigue’ (SBF), a category recommended by the Office for National Statistics for social surveys on disability. Nationally, this impairment type is the second most common among disabled people in the UK, after mobility impairment (Office for National Statistics, 2017).

Our survey suggests that people with impairment of SBF are spread across multiple categories of disease type, as classified by the WHO, the largest being nervous system diseases, and musculoskeletal and connective tissue diseases. This suggests a shared experience of impairment that transcends diagnostic categories and medical classification systems.

This finding is significant because most organisations of, or for, disabled people do not include SBF or an equivalent term, as an impairment type when describing who disabled people are. It is also significant because the WHO’s classification of diseases in terms of function and disability only recognises stamina and fatigue problems in the category of cardiorespiratory disease (WHO, 2002). Our findings indicate that stamina and fatigue problems apply to a much broader range of disease types.

People with SBF and chronic illness may be the second largest impairment group among disabled people in the UK. Yet, effectively, neither medical authorities nor

Disabled People's Organisations (DPOs) adequately represent the needs and experiences of people with chronic illness. The consequences of this under-reporting of, and under-attention to, fatigue, stamina loss and energy limitation are far-reaching, as we will see in Chapter 2.

Therefore, we argue that people with chronic illness who experience SBF are a hidden impairment group. They urgently need their experience of impairment to be heard, and to be incorporated into the lexicon of disability. Without this we cannot hope to inform the design of policies and services to improve the lives of people with SBF and chronic illness.

Recommendations

1. People living with impairment of stamina/breathing/fatigue should be recognised as a discrete impairment group. Disability support systems should be expanded to account for their specific needs and experiences.
2. The World Health Organisation's International Classification of Functioning, Disability and Health should be reviewed considering the reality that problems of fatigue and stamina apply much more widely than the domain of cardio-respiratory medicine.
3. The government should devote specific funding for biomedical (not biopsychosocial) research into pathological fatigue, including its impact on cognitive function, given its centrality in chronic illness experience. The development of biomarkers for fatigue states is crucial for demonstrating eligibility for social support.
4. All functional assessment systems for government programmes of disability support, benefits and concessions should incorporate a holistic understanding of pathological fatigue on function and activity based on the lived experience of people with chronic illness.

2. Chronic illness and ableism

In this chapter we look at participants' feelings about, and experiences of, identifying as disabled. These accounts reveal a form of oppression shared by people with chronic illness. We explore how this experience of oppression fits into the social model framework of barriers to participation and wellbeing. Finally, we discuss how participants responded to the social model of disability as a way of thinking about their circumstances.

Key Findings

1. Attitudes to people with chronic illness are shaped by the stereotype that disability is a fixed and visible form of difference. Pathological fatigue is not perceived as a disability or impairment because it is dismissed as a universal experience. The main form of oppression reported by participants was invalidation and disbelief of their experiences of impairment.
2. Invalidation and disbelief is disabling in several ways: it generates anxiety and distress around disability disclosure, leading to avoidance of disclosure and failure to access adjustments and support; it creates distress and trauma, through feelings of self-doubt and undeservingness; and it creates emotional isolation and the sense that no-one understands, which compounds the isolation from reduced face to face contact.
3. The attitude that fatigue is not a real disability means that systems of disability support are not designed for the impairment experience of people with chronic illness.
4. Focus group participants found the distinction between impairment and disability that underpins the social model to be useful as a tool for thinking about social and political change. Nearly two-thirds of survey respondents said that improved medical treatment was the main thing that could significantly improve their quality of life. However, more than four in five agreed better understanding of and accounting for chronic illness would significantly improve their quality of life.

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Negative attitudes to chronic illness

Our research goal was to explore the experience of chronic illness by disentangling 'impairment' from 'disability'. We therefore aimed to discuss physical, organisational and attitudinal barriers with chronic illness. But before we even mentioned the social model of disability, focus group participants shared distressing experiences of oppressive attitudes to chronic illness. These shared experiences of oppression turned out to form the basis of solidarity within the focus group, which kept it going over eight weeks. It was

very clear that negative attitudes of friends, family members, healthcare professionals and government officials were far more of a concern than physical or organisational barriers. Therefore, the main focus of this chapter is attitudinal barriers. The chapter is divided into describing what the attitudes consist of, and how they are disabling. We then discuss how these experiences of oppression fit within the concept of ableism.

Our initial question to focus group participants: “Do you consider yourself to be disabled?” yielded the most thematically rich and complex material of all the focus group questions. In their responses, rather than giving a ‘yes’ or ‘no’ answer, nearly all participants interrogated the meanings of the term ‘disability’ and qualified their answer with reference to contested meanings.

Identifying as disabled was bound up with participants’ personal trajectories of illness (how long they had been disabled; to what extent they had adjusted to the loss of health and function), but it was equally dependent upon context: who they were dealing with and for what purpose. For nearly all participants, identifying as disabled was a matter of strategy, not their core identity.

Thus, the question “Are you disabled?” was met almost universally with ambiguity and ambivalence. Their agency and choice in identifying as disabled was constricted by social norms and expectations of what constitutes a disabled person that are encountered both in everyday social interaction and in the administrative processes of public bodies. It was felt that there is a hierarchy of signifiers of disability, with wheelchair users and sensory impairments at the top, and fatigue at the bottom.

It certainly feels as if there is a hierarchy amongst disabled people and that those of us that show little or no outward physical signs are at the very bottom.

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The social act of identifying oneself as disabled was fraught with tension. Very commonly, participants said they did not feel entitled to identify as disabled until and unless their status was validated by a government agency, typically through the awarding of a disability benefit.

For a long time, I wouldn't have used the term 'disabled' to describe myself, feeling that I was ill - and that was different. I've recently begun to change that opinion. I'm not sure if that is because it has affected me more visibly. Whether the arrival of a stick, blue badge and PIP have also pulled me up short and made me think differently. I certainly feel that my life is dis-abled by this disease...

I've been registered as disabled for 7 years (in receipt of DLA) and that's when I started to tick the box. I have had Ankylosing Spondylitis for 20 years and even though I had mobility issues as well as pain/fatigue, I didn't feel I had the right till I got that letter.

The largest source of ambivalence towards disability identity is the response of other people to situating themselves as disabled. This was much more of a consideration than any association between disability and tragedy or loss of function.

66% agree that “I would risk negative reactions from others” if they refer to themselves as disabled. In order to investigate whether these ‘negative reactions’ relate to attitudes to disability generally, we compared the response of respondents with visible impairment with those with invisible impairment.

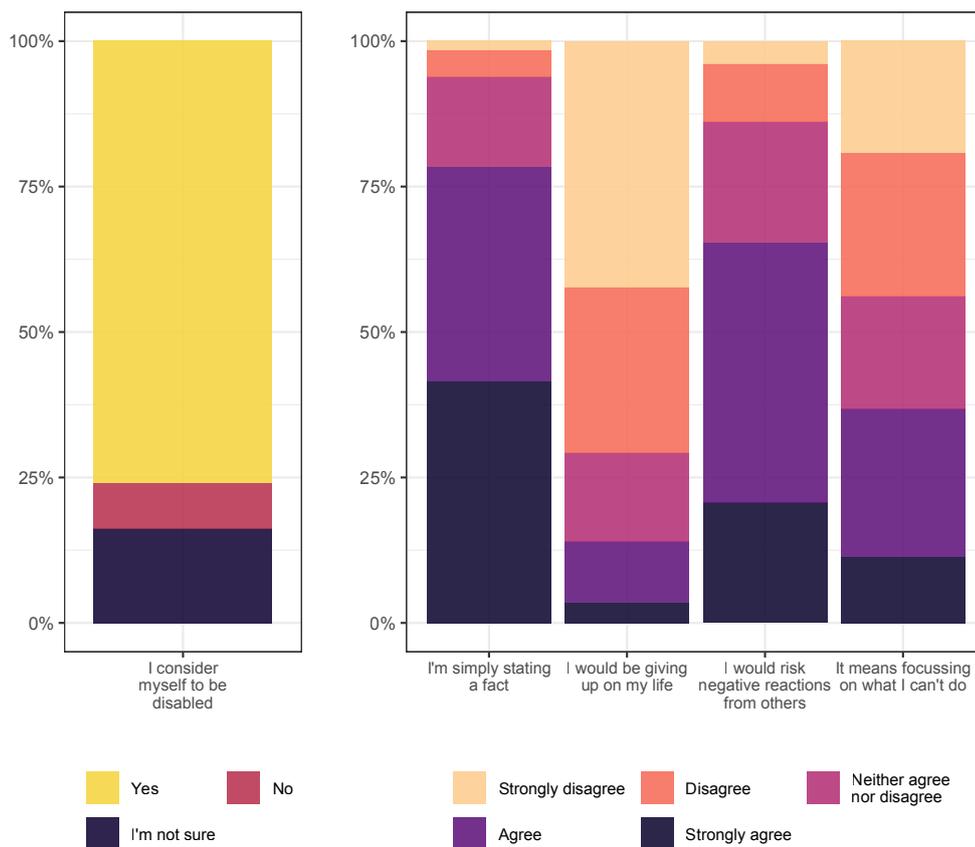


FIGURE 7. Implications of identifying as disabled

Of those with ‘always or mostly’ visible impairment (n=227) 51% said they risked negative response by identifying as disabled. Of those with ‘rarely or never visible’ impairment, 70% said they risked negative response.

The most striking concordance among participants, regardless of their medical diagnosis, was that fatigue was the most restricting, debilitating feature of their health condition, yet the feature that least qualified them, in the eyes of others, to identify as a disabled person. A participant with COPD noted:

My 'real' disability is one that very few people know about and which I'm sure would not entitle me to use the word 'disabled'. I have extreme, life destroying, tiredness. It limits my life far more than my emphysema and yet that's the thing that raises sympathy.

All focus group participants agreed that pathological fatigue drastically redefined their whole existence with the onset of chronic illness. It made them, and their life, ‘different’ and set them apart from the ‘normal’ life they had lost. Yet that was not how other people perceived them and their situation. Whereas ‘disability’ is understood by society as a state of difference, and separation from the ‘normal’, fatigue is thought of as a normal part of human experience. Thus, when participants tried to communicate their impairment experience with others, they were usually met with the response that “everyone gets tired”.

Their experience of difference and ‘otherness’ were dismissed as being illegitimately based on a universal, and quite trivial, part of everyday life.

This lack of understanding, and failure to recognise their difference was a source of much discussion:

I think people in general are bad at recognising the validity of problems that manifest as more extreme versions of common problems. Everyone knows what it's like to be tired so they think they understand the fatigue levels associated with chronic illness when they really don't.

The result of the attitude that “everyone gets tired” is a denial of people’s status as disabled. Participants described interactions, whether with strangers, acquaintances or friends and family, when this mismatch between their embodied experience of impairment and social constructions of disability caused tension and awkwardness.

I know that using the word disabled to refer to myself is an immediate shut down action for a lot of people. They stop thinking about my points and start trying to rationalise why they don't like what I said.

Our survey asked respondents about what kind of attitudes are expressed towards them in relation to chronic illness. Respondents were asked to rate either how frequently they encounter these attitudes or how strongly they agree with the certain statements about other people’s attitudes.

More than 4 out of 5 participants agreed that they encounter the attitude that “everyone gets tired”.

Almost 70% agreed that they encounter the attitude that they “shouldn’t make a fuss” about their difficulties.

55% agreed that they encounter the attitude that “fatigue and pain are not real disabilities”.

Over two thirds frequently encountered the attitude that they “don’t look disabled”.

39% frequently and 44% sometimes encounter the attitude that they “should try harder to overcome their difficulties”.

We wanted to find out whether people with chronic illness encounter common tropes of ableism: pity, being made symbols of tragedy or heroism, the assumption of being less capable than they are.

Less than a quarter (24%) agreed they encounter the attitudes that they are “heroic for living with their health condition”.

Only 21% agreed that “people think I’m less capable than I really am”.

Only 11% frequently encountered the attitude that they were ‘inspirational’, and 10% that their life was a ‘tragedy’ because of disability.

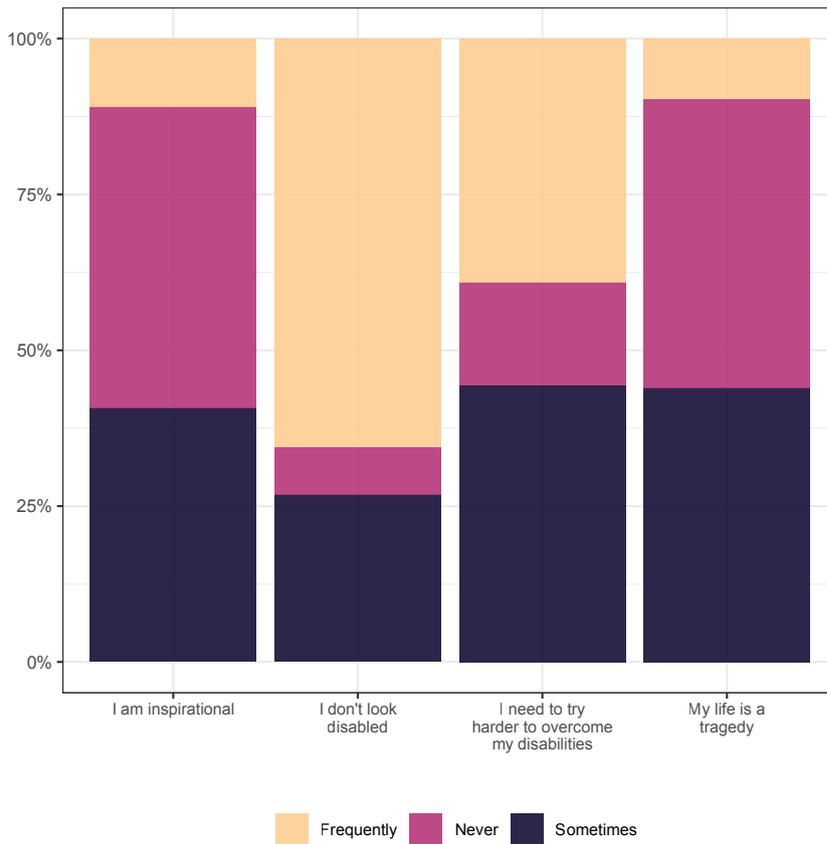


FIGURE 8. Attitudes to chronic illness 1

Participants described that in everyday life, whether identifying as disabled or using strategies to cope with limited energy, their account of reality was challenged and met with hostility.

There's a lot of stigma to putting yourself in the disabled category if the person you're talking to disagrees with you being there. I've had a lot of experiences of others being hostile or patronising (often bizarrely so) because they believe I'm not trying hard enough to be well or am exaggerating my limitations.

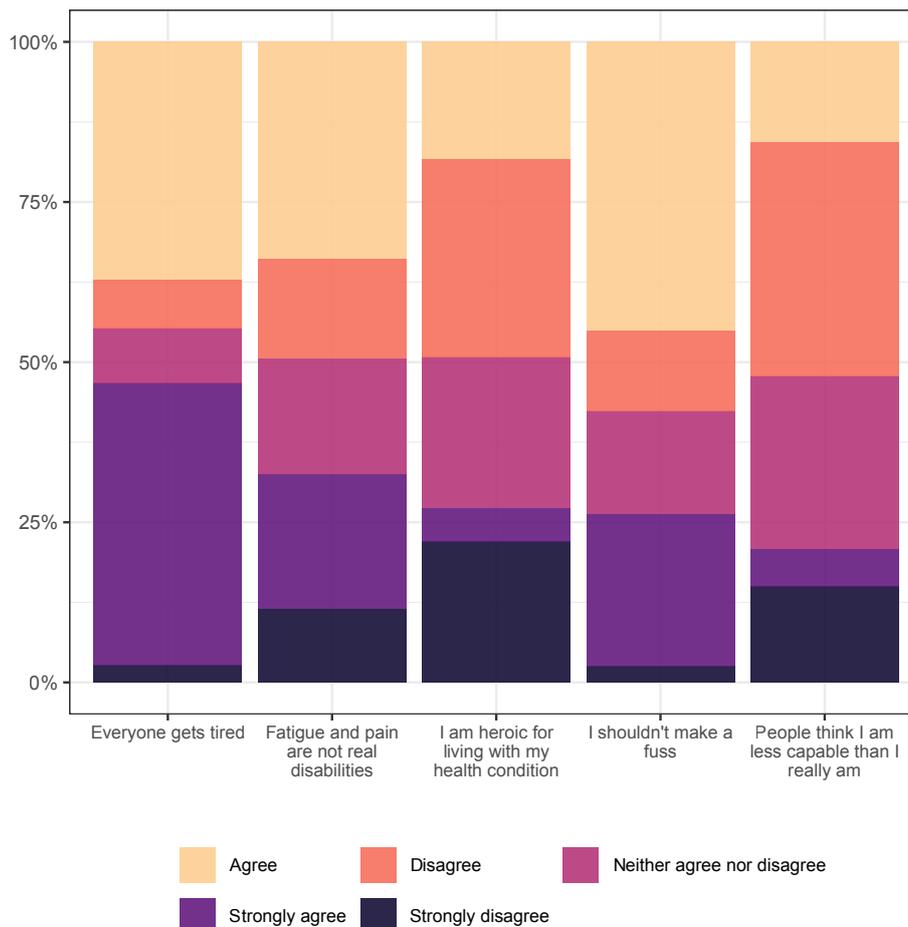


FIGURE 9. Attitudes to chronic illness 2

Often the challenge is implicit, and the hostility is subtle but affecting. One participant described:

“a kind of weird, ambient hostility” ... the feeling that wherever I am, whatever I'm doing, I'm surrounded by people who maybe don't get it and are liable to think badly of me at any moment.

Sometimes participants weren't sure whether hostility was real or imagined, as this account describes well:

[In a group] when we're talking about an event and I say "I don't think I could manage that", there's this pause, and without really being conscious of it at the time I am fearing that they are misunderstanding me, thinking "why is she always going on about being ill when she looks fine, look how chirpy and energetic she looks". People keep telling me how well I look... I don't know if they mean just that or if they are wondering whether I am exaggerating my illness either intentionally or unintentionally. I don't mean that I assume bad motives, but I just never know, and I've experienced so much criticism and misunderstanding.

There appear to be few theoretical tools or concepts from within Disability Studies for exploring these experiences of discrediting and disbelief towards testimonies of

impairment and disability. The philosophical concept of ‘epistemic injustice’ could be a useful framework for exploring oppressive attitudes towards people with chronic illness (see Fricker, 2007; Carel & Kidd, 2014).

Identifying as disabled in situations when impairment is not apparent or easily understandable can create direct social conflict. Several participants shared experiences of overt hostility when positioning themselves as disabled people, for example when using accessible facilities, using mobility aids or claiming disability benefits. These experiences generally involved accusations of exaggerating or feigning impairment in order to obtain certain privileges.

The first time I used a shop mobility scooter, the person in the store when collecting said loudly 'You don't need this!'. I've never hired one again.

When I've been discussing disability benefits with people who don't really know me (on the rare occasion I'm anywhere other than at home!) I've noticed some of them looking very judgmental, as if they're thinking 'well why are you getting that money, you're not 'disabled'. Well, at least not in the way they understand the word.

I was talking to an old friend once about getting my motability car, and she said, repeatedly, "But you're not disabled though" in a blunt, accusatory way.

Recent research from the US indicates that suspicion and accusations of faking and fraud are a common experience for disabled people generally. According to extensive polling (Dorfman, 2020), fear or concern over the potential for ‘fake’ disabled people is widespread among the general public. Moreover, nearly 60% of disabled Americans, including those with visible impairments, feel that others question their disability. This suggests that the oppression faced by people with chronic illness is not unique to them, but an aspect of broader attitudes towards disabled people generally.

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Internalised oppression

Feeling like a fraud

The participant who was challenged by a friend about having a motability vehicle noted:

I was quite upset about her tone and her insistence, and I only challenged her lightly. I hated that she made me feel like a fraud and made me worried that she would report me to the DWP.

Hostility, whether in the form of implicit disbelief, or the overt violence of accusations of faking disability, caused enduring distress beyond the encounter itself. Repeated exposure to this kind of invalidation of their impairment experience seemed to be internalised by many participants into “feeling like a fraud” generally. As a result, most participants reported having to grapple with the feeling that they were not entitled to refer to themselves as disabled.

As for the label of 'disabled', yes, it's such a loaded term and I feel as though I'm lying if I say it. Isn't that odd?

This extended to their sense of entitlement to disability-related benefits:

Even when I was granted DLA I think I still felt a bit of an imposter. I applied for low rate and CAB said I should be on high rate. Sometimes I think I'm just lazy.

Our survey asked about the impact that social attitudes to chronic illness have upon wellbeing and sense of self. We asked to what extent respondents feel “like an imposter” when referring to themselves as disabled, and how frequently they feel anxious in public due to fear of surveillance or judgement in relation to disabled status.

43% of respondents agreed that “I feel like an imposter” when referring to themselves as disabled. The rate of agreement to this statement from respondents with visible

impairment was much lower (25%) than among those with invisible impairment (54%).

41% said they ‘frequently’ feel anxious about being watched or judged about my disability in public spaces. A further 40% said they ‘sometimes’ feel anxious in this situation, and 19% said they ‘never’ feel anxious in this situation.

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Whilst focus group participants would insist that chronic illness in itself is disabling, it was clear that some of their social and leisure activities or participation were prevented not by their impairment itself, but by disabling social attitudes. They gave many examples of how repeated encounters involving invalidation, disbelief and direct accusations of faking led them to avoid activities.

People seem to feel they have a right to demand I justify myself or they want to give advice... I always find these kinds of interactions very draining so I try and avoid them.

If I [undertake therapeutic walking as medically advised] you can guarantee that someone will see me and think I'm lying, I'm faking, I'm making a false claim for disability mobility allowance.

I would love to try to play bowls because there are only short bursts of movement and plenty of recuperation in between - but when you see so many negative articles about disabled people playing golf etc...

These examples of social avoidance due to surveillance and suspicion extended also to interaction on social media.

Since becoming ill (well, more ill!) and having to deal with DWP and the like I decided to make my twitter profile even more anonymous so it doesn't use anything like my real name, no photos and I don't share where I am or a location at all... I feel I can talk more freely that way...I don't feel afraid to share when I have a good day too.

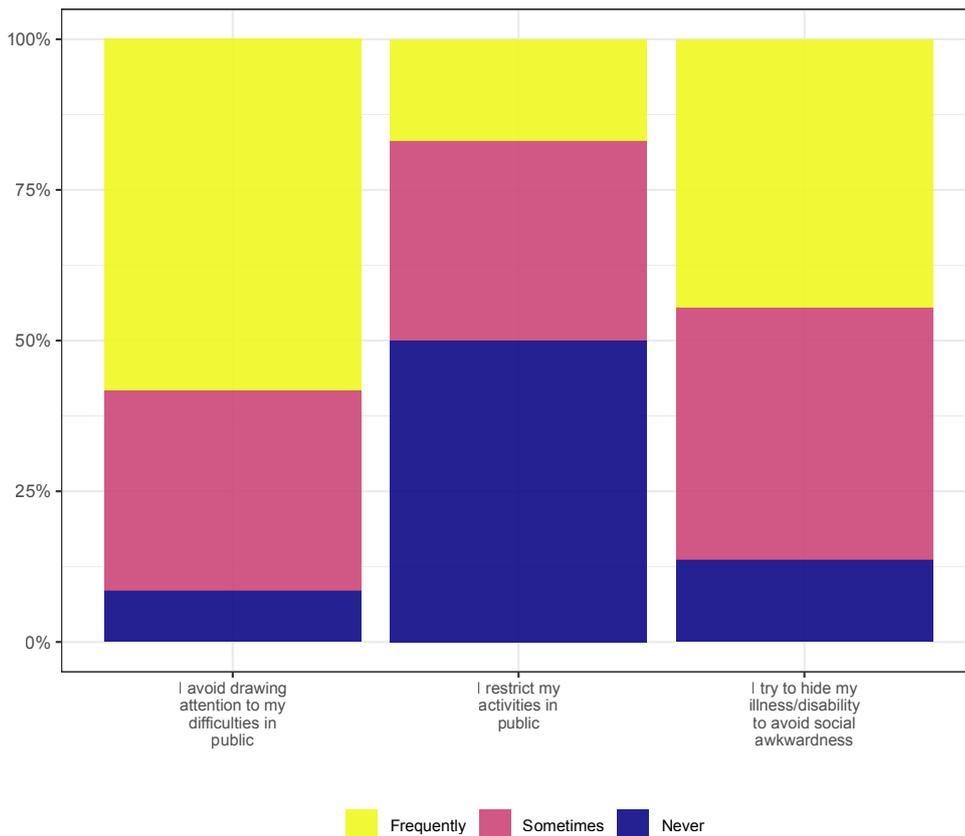


FIGURE 10. Impact of attitudes to chronic illness 1

Our survey also asked about how attitudes to chronic illness create barriers to participation. This could be either because of an impact on how they are able to manage their condition and support needs in a public sphere, or because of social withdrawal caused by stigma and anxiety.

Almost 60% said they ‘frequently’ avoid drawing attention to their difficulties in public, with another 33% doing so ‘sometimes’.

45% frequently, and 42% sometimes, try to hide their illness/disability to avoid social awkwardness.

Half of respondents said they frequently or sometimes restrict activities like walking in public “in case I appear less disabled than I am”.

37% said they avoid talking to new people in case they have to disclose their health condition/disability.

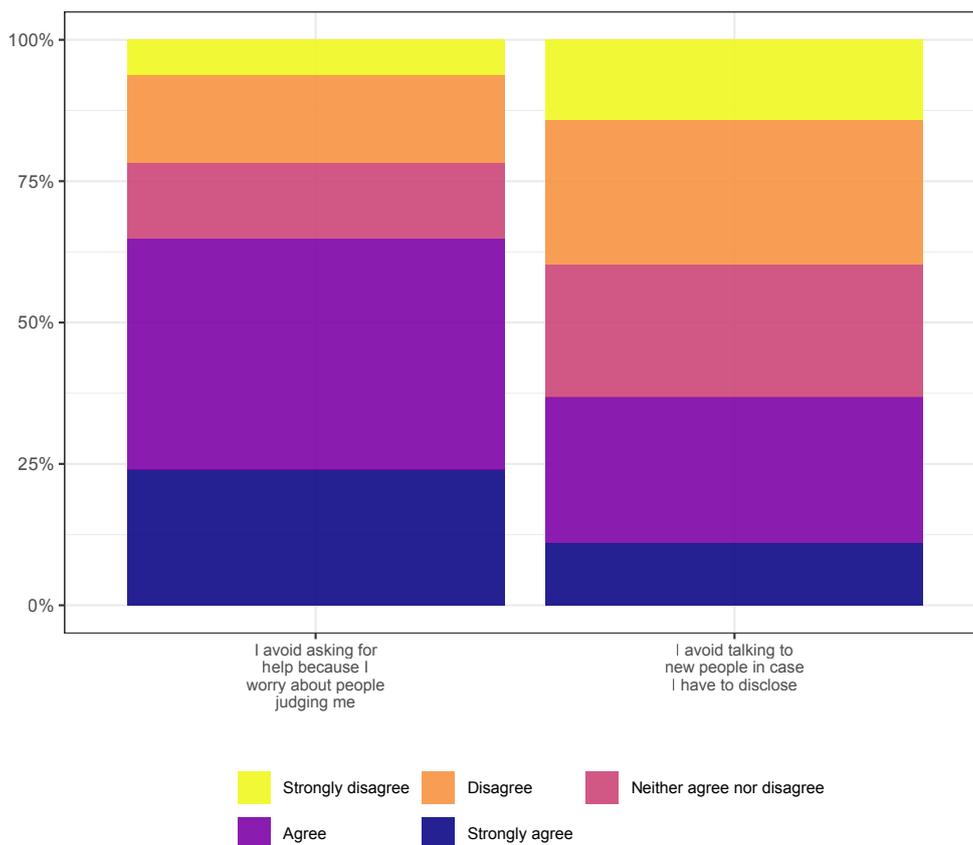


FIGURE 11. Impact of attitudes to chronic illness 2

The implication of the attitude that “everyone gets tired” is that overcoming fatigue is seen as a matter of willpower and moral strength. The idea that the failure to manage or overcome fatigue is a personal and moral failure was very strongly entrenched in some participants, and one they had to struggle hard to overcome. For some this was an ever-present source of mental distress:

I feel anxious every day about what my husband and family are thinking of me, whether people think I am weak, lazy, selfish and so on.

Several participants described how, at the onset of illness, they themselves subscribed to the notion that fatigue is a universal experience that requires effort to overcome.

I thought ‘oh, I get more tired than other people, it must be cos I’m fat/unfit/lazy’ and I blamed myself! And teachers/employers would assume it was my fault too—tell me to get fresh air, go for a run etc. This past experience of it still makes me feel a fraud today. I forget that fatigue is literally part of my illness and my gut response is ‘oh god, I’m just being lazy, I should do some activity’.

I still have an issue with self-esteem though and feel that if I identify as disabled that someone with a ‘worse’ or more visible disability will think badly of me for taking resources away from them. Or that people might think that I’m faking it for attention, or to get concession theatre tickets or I’m lazy and want to sit down.

Performing ‘normal’ or ‘trying hard’

Several participants discussed, often in joking terms, the irony that while they were accused of faking disability, what they were really faking was being ‘normal’.

I fake being well brilliantly... if I do say so! Lol. I think we could win Oscars!

They recognised that faking ‘normality’ was a compulsive act that they performed, often without awareness, and is directed to managing social tensions and conflict.

I definitely 'put on the mask', partly with those I don't want to worry too much about how bad I really am (mainly my (adult) children) and partly for myself, because I desperately want to be the old capable me that people know/knew.

Some participants noted that the compulsion to pass as ‘normal’ was ultimately counter-productive because it reinforces the oppressive stereotype that chronic illness and fatigue are not real disabilities.

[The performance] is not for our benefit in the end. It's for theirs... Of course it's a double edged sword in that it also reinforces the perception that we're not really suffering.

The compulsion to pass as ‘normal’ also entailed acquiescing to arrangements that exacerbated their impairment, and feeling unable to assert their needs as disabled people, as this vignette of an encounter on public transport illustrates:

*Other passengers can be really judgemental. They see me as a youngish, healthy *looking*, well groomed... woman who is smiling and assume I'll be as healthy and fit as I must look. A woman with her husband started complaining to me and making a fuss that I wouldn't move from my booked aisle seat to the window seat so they could sit together. I needed the aisle seat as my leg really needed to stretch and it's just much more comfortable for my sciatica to be able to move more. I can't very well shout "I'm disabled you know!!" So I ended up just going to another aisle seat elsewhere.*

On the other hand, participants also reported feeling compelled to demonstrate that they were “trying hard” to overcome fatigue and pain, sometimes to the detriment of their health.

I feel that in a lot of social contexts we're expected to demonstrate that we're trying very hard to overcome our problems and not being soft on ourselves before people will treat us without suspicion.

I feel like every day I am battling to prove myself – that I am really this sick, that I am working hard, how exhausted I feel, how difficult things are for me, in order to avoid their judgements. But it feels like standing on the beach with a bucket trying to stop the tide coming in. No matter how hard I try, I can't help their comments and attitudes creeping in and making me question myself.

The Impact of negative attitudes

Our survey asked further questions about how attitudes of disability denial and disbelief shape their own thoughts, behaviour and connection to society.

42% agreed “I sometimes doubt whether my condition is real”.

65% of respondents agreed they felt a need to prove how hard they were trying to overcome their disability/health condition.

More than three quarters of survey respondents agreed “I feel isolated by people's lack of understanding of the impact of my health condition(s)”

The mismatch between lived experience of chronic illness and social constructions of disability was a common topic among focus group participants. It seems clear from our survey findings that invalidation and disbelief give rise to emotional isolation. This is an additional layer of isolation to the reduced face-to-face contact reported by participants as a result of having to withdraw from many, or all, forms of social participation.

Research shows that social isolation and loneliness are key determinants of negative health and wellbeing outcomes (Holt-Lunstad, Smith, & Layton, 2010). We should, therefore, be very concerned by our findings, which provide direct evidence that invalidation and disbelief are potentially disabling in their impact on overall health.

When material, structural or organisational barriers were mentioned by participants, they often turned out to be rooted in attitudinal barriers, namely stereotypes about disability as a fixed and visible state, and the attitude that fatigue is not a real disability. (When we asked participants directly about socially created barriers to activity and participation, those who used mobility vehicles mentioned environmental barriers to level access. We do not discuss these in detail as they are common to people with mobility impairments.)

Discussion about societal barriers with chronic illness brought us back to our initial observations that fatigue and energy limitation are not perceived as a form of disability, but as a universal, and relatively trivial, experience. This attitude appears to lead to the assumption that legal duties or social obligations to remove barriers to participation for disabled people do not apply to people with chronic illness.

The most common form of material barrier not relating to mobility vehicles was inappropriate seating. Type of seating was a strong determinant of whether non-wheelchair users were able to take part in social or leisure activities.

I choose nights out by how comfortable/supportive the seating is. I often turn up with ice packs on the painful bits and cushions to make seating easier. I get funny looks but hay ho.

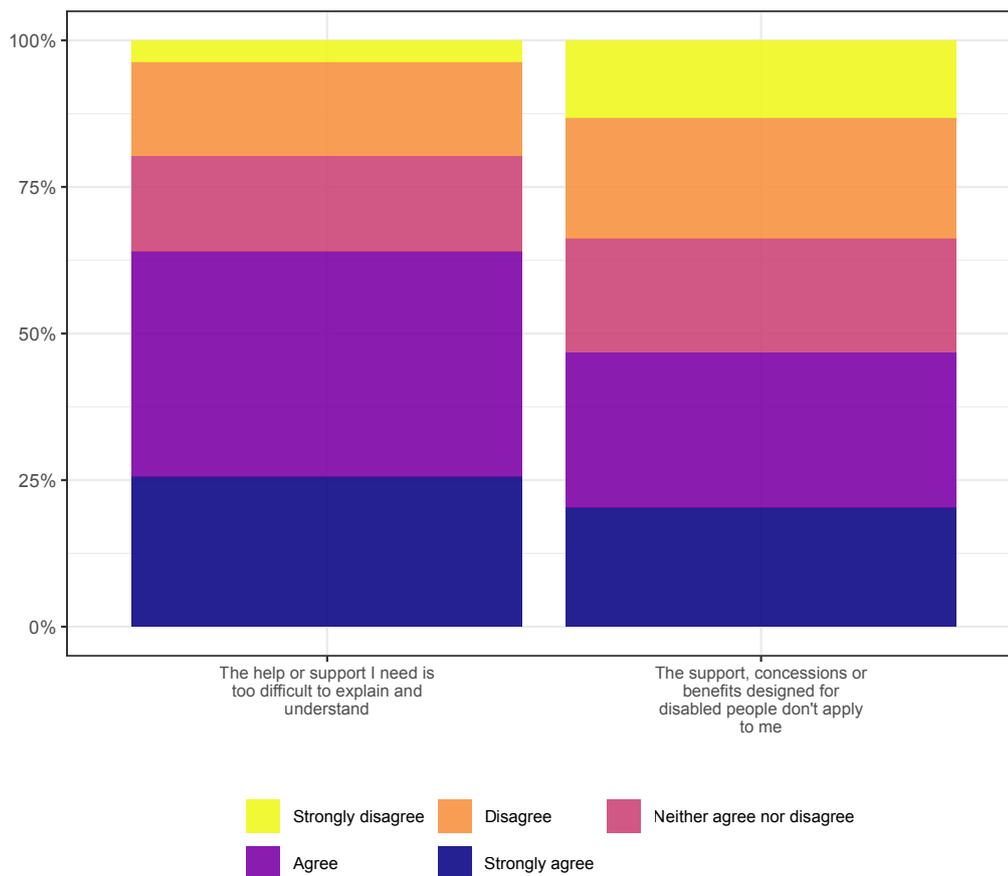


FIGURE 12. Barriers to access

Considerations included:

Does it have the right padding in the right places? At the correct height or angle? Is there some way I can raise my leg etc.

But participants noted “no one even thinks about this or thinks it’s an issue”, because seating type is considered a personal preference, not an access requirement.

Another common problem mentioned was the organisation of meetings and events. Many participants said their fatigue and energy limitation was more severe in the evenings and this excluded them from engaging in local community activities. Requests to change the timing of meetings were dismissed:

I have particular problems with evening meetings, my fatigue and sleep apnoea mean it is impossible for me to attend. What makes it more frustrating is when groups are informed of this and still refuse to even try to facilitate my access by trying day time/weekend events.

I support a political party but ALL of their meetings are held at night when I'm too exhausted to attend - and the nastiest comments I've received, ever, were from a member of this party who objected to my absence.

Participants expressed frustration that access needs not relating to ramps or lifts were often dismissed as stemming from individual or idiosyncratic preferences, rather than to impairment. In relation to evening meetings:

Clearly then, they don't accept fatigue as a reason to not attend and they don't think they need to vary the times of their meetings.

Another participant said that even when she had made efforts to explain her needs, the response was that they were too complicated to consider.

It is so much easier for people to respond to a need they can see than one that has to be explained. I have at times taken great energy to spell out exactly what my issues are and what would help me. But it seems too overwhelming for them. This makes me sad that I'm not important enough or frustrated that they don't care.

Emancipation - giving myself permission to identify as disabled

For all but one participant (whose impairment was visible and present since childhood), occupying the socially constructed and socially protected category of 'disability' was an act of emancipation.

For most participants, the journey from identifying as 'ill' to identifying as 'disabled' occurred when their functional restrictions forced them to stop working. Once they had to begin navigating the social security system, they confronted social stereotypes of disability in the form of eligibility criteria.

Identifying as disabled took time and a labour of self-belief to resist powerful social norms and stereotypes about who disabled people are and are not. It involved navigating difficult and hostile encounters of dismissal and disbelief and overcoming internalised messages of invalidation. It entailed asserting that the lived experience of impairment takes priority over common understandings, or medical accounts, of illness and disease.

At first I thought I just had to struggle on and I wasn't 'worthy' or 'bad enough' to allow myself to be thought of as disabled. But I came to understand that I AM allowed to call myself disabled. I AM allowed to have accessibility needs. Looking back, had I asked for more help and accepted my disabilities I could have saved myself a lot of pain, fatigue and emotional stress.

Participants who most identified as disabled had come to embrace disabled status as a gateway to support and accommodations which enabled them to lead a fuller life. Identifying as disabled enabled them to free themselves of the compulsion to perform normality or to demonstrate how hard they were trying to overcome illness. Thus it freed them from self-imposed standards they could no longer live up to.

For me, [identifying as disabled] was liberating. It opened up the world again. Because I could park nearer and get out the car easier with opening doors wide, I got out more.

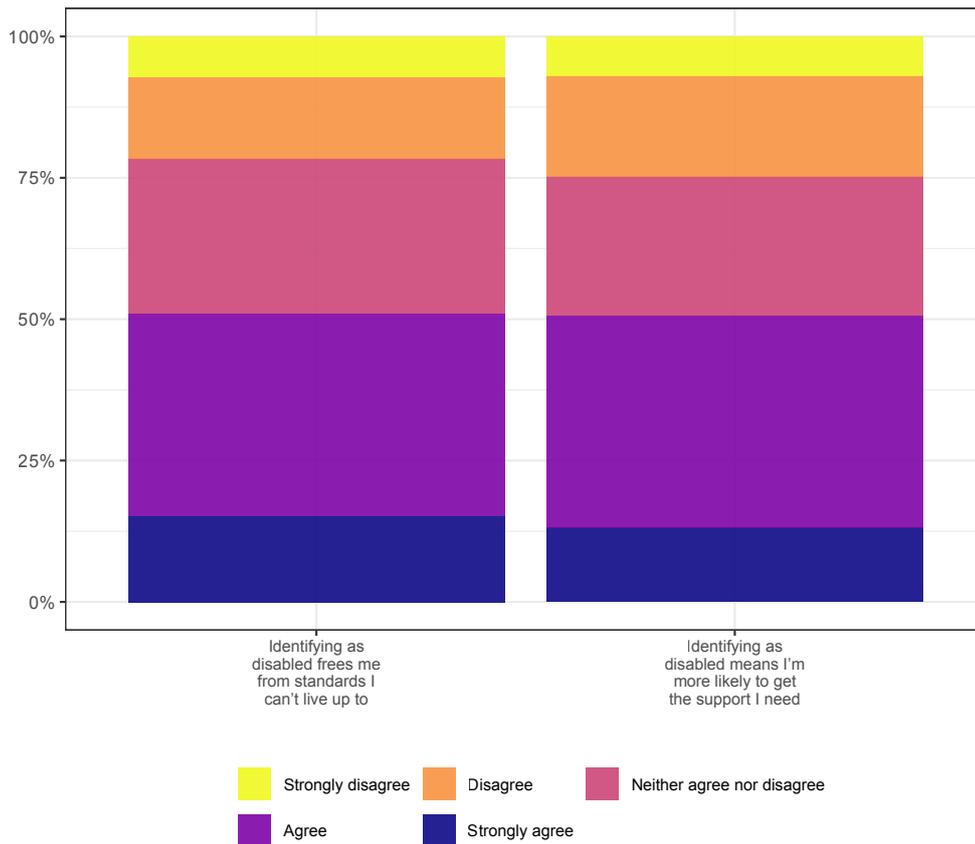


FIGURE 13. Benefits of disability identity

Participants’ response to a social model of chronic illness

Only at the later stage of focus group discussions did we formally introduce the social model of disability. We asked participants to respond to the conceptual distinction between impairment and disability, with the aim of developing a social model of chronic illness. One participant unreservedly welcomed the conceptual distinction between impairment and disability as a tool for emancipation:

I think it is helpful. It is important to know when the things I can't do are due to my condition, because then I know I have to come to terms with them. But where it's down to society, I can campaign for change, even in small ways.

Most other participants were cautiously open-minded about the usefulness of the distinction between biological and social causes of disadvantage. Several people said they had not encountered it before, found it difficult to grasp, but interesting to grapple with.

I suppose I think the distinction is really important but I've not spent much time thinking about it until recently...I need to think harder to work out exactly what would be helpful as I'm so used to 'just struggling with it' and working solutions on my own. Really, wider societal changes would help, I just sometimes don't realise.

However, despite welcoming the impairment/disability binary as a tool for thinking about social change, there was widespread resistance to the idea that the term ‘disability’ should only apply to external, societal factors, and not to embodied experience. A number of participants felt it was ‘jarring’ to place the problem in society, rather than in their illness:

I don't have a hang up with using the word disability. Description of disabled to me is what stops me from doing what the able bodied can do.

I don't like the word impairment. I'm not sure if I can fully explain why. It just makes me feel weak and I think the word has less impact.

Those of us limited by pain, fatigue etc, who can walk around looking as if we are well and able, are still DIS-abled. My fatigue is disabling.

Participants strongly defended their use of the term ‘disabled’ to refer to their bodily malfunction and incapacity with chronic illness. One participant asserted that she was disabled by society. But all the others insisted that their malfunctioning body was the primary cause of their activity restriction or disablement, and that external factors like adjustments, support, aids or adaptations could help to some extent but could never fully mitigate their impairment:

No matter how many adjustments may be required by the external world it makes little difference if you are too unwell to get out of bed.

With fatigue as my main disability it's not as simple as wheelchair accessibility, people knowing BSL [British Sign Language] and so on (not meaning these are simple to achieve).

I feel a lot of my restrictions are faced by my health condition - sheer exhaustion is what stops me most, stops me doing things I want to - and nothing external can help that.

Being able to sit or even lie down for a break would help I guess, but I'd still have to pay the price the next day or week and then struggle to meet my commitments.

There were other aspects of chronic illness experience that participants felt were at odds with the social model of disability, such as not having ‘pride’ in their disabled bodies and longing for a treatment or cure for their illness.

Despite this unwillingness to disentangle disability from the body, all but one participant expressed the conviction that their life would be better if there were greater understanding and acceptance of chronic illness, and if society believed and respected people with chronic illness. And, while most made it clear that barrier removal would never fully mitigate the restrictions caused by chronic illness, they acknowledged that changes in attitudes and provisions would go a long way towards reducing their disadvantage and exclusion.

Thus understandings disability among participants were more aligned to a Human Rights model of disability, which allows consideration of both biological and social factors, than to a strict reading of the social model which locates disability entirely outside of the body. The UNCRPD defines disability as “long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (UNCRPD, 2016, p4).

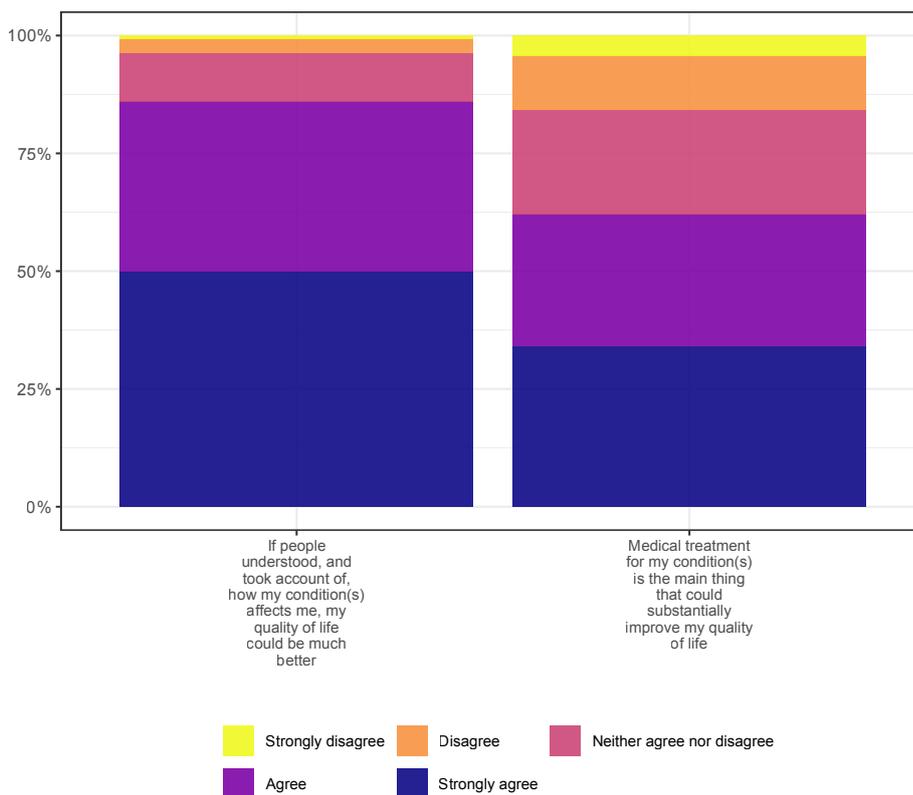


FIGURE 14. Medical vs social approaches to chronic illness

Proponents of the social model have imposed a dichotomy between the medical model and the social model of disability, implying that pursuing medical intervention and cure is incompatible with disability activism. However, our survey results suggest that, at least for people with chronic illness, this is a false dichotomy:

- ◆ People with chronic illness want improved health more than changes in social and political responses to chronic illness. 62% agreed that, “medical treatment for my condition(s) is the main thing that could substantially improve my quality of life” (34% strongly agreed).
- ◆ This is not incompatible with wanting to change how society responds to chronic illness. 86% agreed that “if people understood, and took account of, how my condition(s) affects me, my quality of life could be much better” (50% strongly agreed).

Discussion: expanding understandings of disability and ableism

Our research findings suggest that the oppression reported by people with chronic illness mostly takes the form of invalidation and disbelief. Developing an understanding of how chronic illness leads to disability leads us to an important question: how does the invalidation and disbelief experienced by people with invisible and chronic illness fit within existing understandings of ableism?

Ableism relates to the treatment of disabled people as inferior, and less than fully human (Campbell 2009). It manifests in the shunning and segregation of disabled people, in attitudes of pity and paternalism, or through the symbolism of tragic or inspirational heroes. Ableism is often discussed synonymously with disability discrimination. However, people with chronic illness are not seen as, or treated as, 'different'. And they encounter hostile treatment not on the basis of impairment or perceived impairment, but on the basis of denial of impairment.

Our research findings suggest that the hostile invalidation and disbelief of people who do not meet social constructed norms of 'disability' arise out of society's perceived need to protect the social status of 'disability.' The oppression described by participants centred on a policing of the divide between 'normal' and 'disabled' bodies, whether by professionals, government agencies or the general public. This would suggest that invalidation and disbelief are not a separate form of oppression to that experienced by people with visible impairments. Rather, they are a core and constitutive feature of ableism.

Focus group discussions powerfully demonstrate that stereotypes about disability and disabled people and negative attitudes to fatigue form a disabling barrier to living as well as possible with chronic illness. However, although incidences of disbelief and hostility were frequently mentioned by participants, they were rarely framed as structural barriers. Instead they were expressed in terms of self-doubt. This suggests that the oppression of people with chronic illness is strongly internalised, and that the concept of 'psycho-emotional disablism' could be useful for understanding these processes and addressing their impact (Reeve, 2011; Thomas, 1999).

Participants who did, over time, learn to challenge this oppression all agreed that identifying as disabled was liberating. They reported leading a fuller life, feeling better adjusted to living with chronic illness and managing their health better. We conclude that people with chronic illness need peer support and encouragement to challenge internalised oppression.

The ableism encountered by people with chronic illness is not discrimination in the legal sense, nor does it fall within the scope of disability hate crime. We may experience disability discrimination, arising from a failure to make reasonable adjustments to enable our social participation, as well as invalidation and disbelief. But unless our legal status as legally disabled people is validated we have no recourse to anti-discrimination laws. This means that people with chronic illness currently lack an effective legislative framework for challenging our oppression.

Recommendations

- 1.** Organisations of, and for, disabled people should include and represent people with chronic illness and energy impairment in education and training on access and inclusion.
- 2.** Organisations of, and for, disabled people should challenge ableist attitudes and practices in all their forms and manifestations, including invalidation and disbelief. People with chronic illness need peer support to identify and overcome internalised oppression.

3. Towards advocacy

In this final chapter we consider how to take action to challenge our oppression as a hidden impairment group and mobilise a collective struggle for influencing the decisions made about our lives. We explore a) how to increase our visibility through the development of a stronger identity for people with chronic illness, and b) what are the most pressing social and political issues we need to address.

Key Findings

1. Focus group participants expressed a strong commitment to advocating for their needs and rights as an impairment group that is broader than their individual diagnostic labels.
2. Participants recognised the need for language that is more descriptive of impairment than the term ‘chronic illness’. There was widespread dissatisfaction with the term ‘fatigue’, and a sense that this language is a cause of our oppression.
3. The term ‘energy limiting chronic illness’ (ELCI) as a descriptive label of their identity as disabled people was strongly preferred over existing terms. The term ‘energy impairment’, as a broader category that can include people who have energy impairment as a secondary issue rather than from ELCI, was widely accepted as an alternative to the term ‘fatigue’ and was preferred over the concept of ‘stamina impairment’.
4. Respondents’ policy priorities were healthcare and social security, with Personal Independence Payments (PIP) a particularly strong priority. Interactions with DWP staff and healthcare professionals were perceived to be the main source of oppressive attitudes towards people with chronic illness.
5. Issues of independent living such as social care provision, and choice and control over support are near the bottom in terms of policy priorities, notwithstanding evidence of need for care and support in daily living.
6. Social isolation, social exclusion and stigma were felt to be the biggest social issues affecting respondents’ lives. Disability discrimination and, surprisingly, poverty, were rated as the least important issues. The most important aspects of citizenship were having a sense of meaning and purpose in life, and having relationships of love.

Towards a language and identity for advocacy

When we asked focus group participants why they had applied to take part in the CIIP, the desire to be part of an advocacy movement for people chronic illness was a common theme. Participants mentioned wanting to have a ‘voice’, wanting to influence policy decisions, feeling dissatisfied with existing DPOs, wanting to make a meaningful contribution to society and wanting to build a platform for change that is broader than individual disease communities.

I volunteered to be part of this research because it's important for people with chronic illness to have a voice.

We would definitely work better as a group, as has already been shown by disability rights group.

The more we're split off into smaller groups, the less visible we are and the less of a voice we have. And we need all the help we can get to make ourselves heard, since we also have the issue of being limited in what we can do.

If we have more of a voice, our numbers are seen and our predicaments better understood, then we will have to be treated better by those who have power over our lives.

I'm particularly excited to be involved in this project because I've had poor experiences trying to be involved in disabled politically active groups. I find there tends to be little interest in chronic illnesses.

It's an opportunity to help the people who make decisions that affect our lives (or those who influence them), understand our situations and choices, or at least make it more difficult to defend things like the gaslighting monstrosity that the benefits system is increasingly becoming

I've joined a few DPOs but I'm unable to physically get out and protest or attend events which means I'm mostly unable to participate.

I struggle with feeling quite helpless in the face of my illness and being unable to work, so this is a way to feel like I'm contributing to the chronic illness/disabled community.

Focus group discussions explored language and terminology for conveying our identity as disabled people, raising our profile and getting our voice heard.

We need an identity to be seen.

I feel that it is important for people to have a language with which they can describe their experiences. I feel that the more variety of descriptions we share the more chance someone will think 'oh, me too!' And you feel less isolated.

They acknowledged that 'chronic illness', the most commonly used and acceptable identity within the online community, has broad and non-specific meaning outside the community and has declined in usage in both clinical and social policy in favour of 'long-term health condition'.

Focus group participants felt that although 'fatigue' was the most common and the most restricting aspect of their impairment, the term 'fatigue' was inadequate as an explanatory tool. There was broad agreement that the term 'fatigue' and its connotations, is in itself part of the problem because it evokes 'normal', everyday, and relatively trivial experience.

I really don't like the term fatigue, it makes me think of fainting couches and indolent Jane Austen characters. I don't think it adequately conveys how severe, constant, body/mind consuming and limiting the exhaustion is.

I agree that 'fatigue' is not necessarily a useful term. People just think, "Oh that means tired all the time, aww shucks" or "Oh well I'm tired all the time too because I work and have kids" or whatever.

I'd rather there was a different word that doesn't just sound like "tired all the time"

It would be great if someone could come up with one that encapsulates the full effect of chronic illness - an all encompassing label that meant people, especially policy makers, could understand instead of having to list a string of symptoms

Almost all participants had come across the term ‘spoonie’ via the internet, as a transdiagnostic label of identity used by some people with chronic illness. Most said that although the description of spoons as limited units of energy applied to them and they sometimes found it useful as a tool for getting friends and family to understand, they didn’t use it as a badge of identity because they found it “silly”, “infantilising”, “cliquey” or “too perky” and “fluffy”.

We therefore proposed alternatives to ‘spoonie’ or ‘chronic illness’. The term *energy limiting chronic illness* was a popular choice in the focus group. We wanted to explore whether it would be preferred over the existing labels used by the disability sector and by policy makers. *Long-term health condition* is commonly used in social surveys on disability to capture impairment that is not easily categorised under well-defined impairment types such as visual impairment or mobility impairment. *Fluctuating condition* has been used by policymakers to encompass conditions characterised by fatigue and pain, notably in relation to the Work Capability Assessment (Harrington, 2011). However, many fluctuating health conditions are not characterised by fatigue; and fluctuation may not be a prominent feature of an energy-limiting condition.

‘Energy Limiting Chronic Illness’ was preferred by respondents to both ‘Long Term Health Condition’ and ‘Fluctuating Condition’ for describing their type of health condition(s) to those who need to understand (see Table 2).

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Preferred Term	First choice	Second Choice
Energy Limiting Chronic Illness	53%	29%
Fluctuating Condition	13%	30%
Long Term Health Condition	36%	40%

TABLE 2. Which of these labels best describes your type of health condition and its impact on day to day life?

We proposed the term *stamina impairment* to participants in our focus group because it is already part of the language recommended by the Office for National statistics for social surveys on disability, albeit rarely used. We felt that defining chronic illness as an impairment type is important for achieving parity with other impairment groups and for alignment with the social model of disability and its impairment/disability binary and therefore the disability sector generally.

Because of resistance to the term ‘stamina’ in the focus group, we offered survey respondents the alternative of ‘energy impairment’. Many commenters on the survey also objected to the term ‘stamina’. One respondent’s response sums up the comments of many others:

*Stamina impairment carries connotations of laziness as it is something able-bodied people can build through exercise. It would lead to even more bulls**t where people think we're just lazy & more medical professionals dismissively telling us we're just "deconditioned".*

72% agreed that the term energy impairment describes the impact of their health condition on their life, with a further 15% saying 'sometimes'. In comparison, 62% endorsed the term stamina impairment, with 14% endorsing its use "sometimes".

Only 9% of respondents rejected the term 'energy impairment' altogether. Although acceptance of the term was high, it is important to note the objections of a minority. Among those who commented, there was some general dissatisfaction with the terms, including the failure to convey pain or the combination of physical and cognitive impairment.

There were a number of comments on the term 'impairment'. All these comments were to the effect that impairment is "not a strong enough term to use"; diminishes the overall impact of illness; does not convey its catastrophic, "life-altering" impact, or the "total loss of function"; and does not describe the global nature of impairment: "There's no area of my life that isn't impaired". Some expressed preference for a metaphor like 'spoon theory' to the term 'impairment'.

We propose that communicating energy impairment as a spectrum from mild, moderate to severe may help in overcoming the objection that impairment is not a strong enough term.

Towards an agenda for social and political change

The limited timeframe of our focus group meant there was not sufficient scope for developing an agenda for social change through in-depth discussion. We therefore used the survey to gauge broad policy priorities and issues of importance to people with chronic illness, in order to give indicators for future work.

Respondents were asked to rank areas of social policy according to importance for improving their lives. Whichever way we present the results, it is clear that healthcare followed by benefits are far and away the most important policy priority areas for survey respondents. Accessible transport is the lowest priority, slightly below education. 94.9% of respondents are aged 25 or over, and so much less likely to be in school, college or university. Many respondents are likely either largely housebound, or find transport to be sufficiently accessible. Only 2.7% of all respondents with a view on transport rated it as their highest priority area.

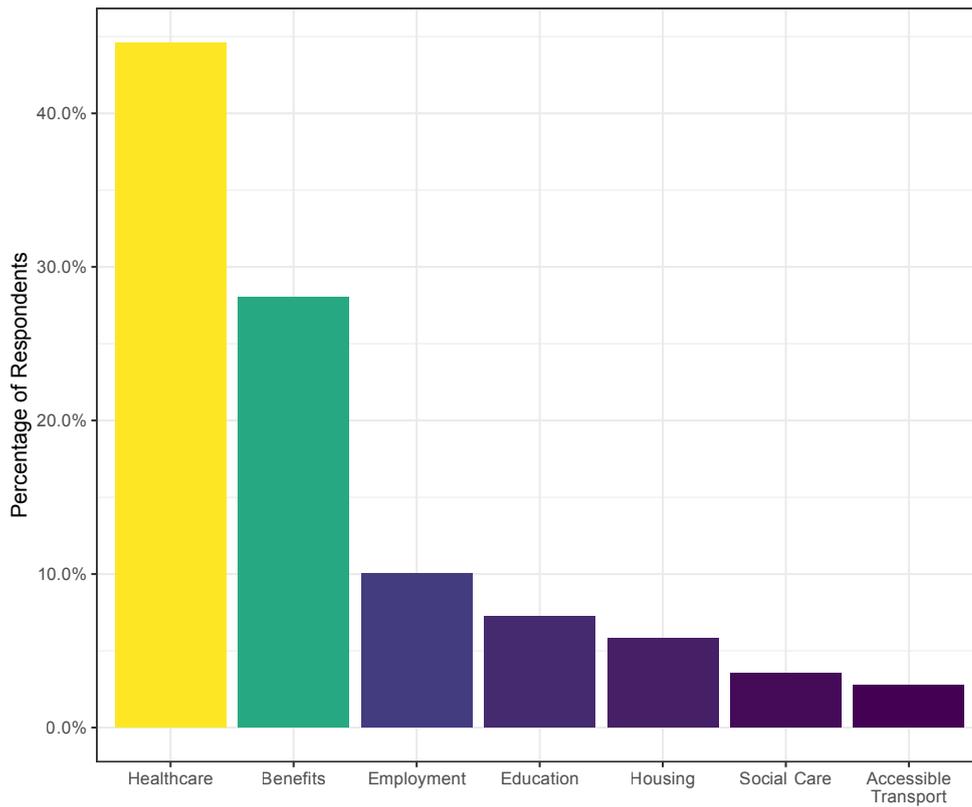


FIGURE 15. Social policy priorities

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We then asked for respondents’ priorities on policies targeted specifically to disabled people. We asked them to select their top three priorities, then rate the other choices as “very important”, “quite important” or “not very important”.

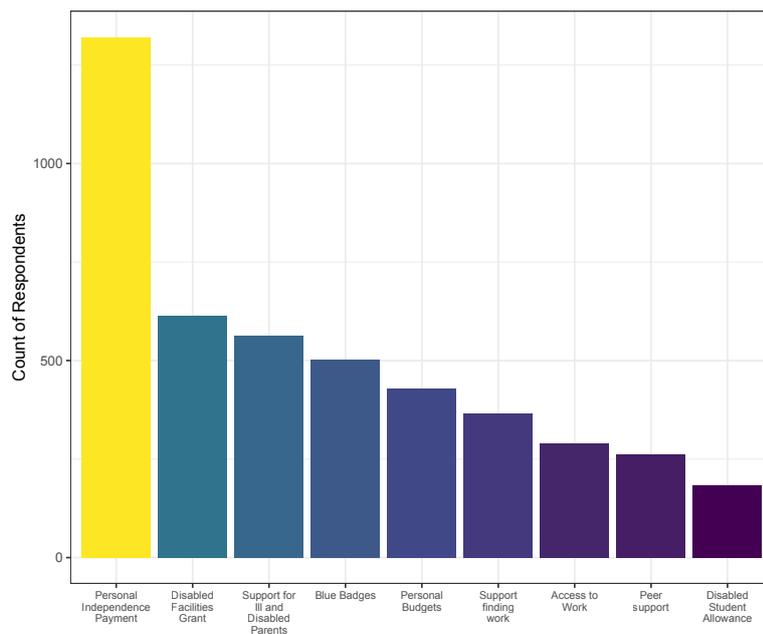


FIGURE 16. Disability policy priorities

More than four in five respondents identified PIP as a top three priority issue for them, far outstripping Disabled Facilities Grants, which was identified as top three priority by 38% of respondents. This was followed by support for disabled parents (35%) and the Blue Badge parking scheme (31%). Special educational needs may have ranked low because fewer than 1% of respondents was under 18. The low rating for Disabled Students Allowance probably reflects the fact that only 5% of survey respondents were in the 18 to 24 age range. Personal budgets/direct payments, employment support and Access to Work were all relatively low priority areas of policy. Possible explanations for these results are that respondents may not have been awarded a social care package, or been led to believe they would not qualify for one. Also, they may not have been in work, or looking for work.

Following on from survey questions about negative attitudes to chronic illness, respondents were asked whose attitudes, from a range of social actors, had the most negative impact on them. The highest percentage (44%) of respondents selected the attitudes of the Department for Work and Pensions as having the most negative impact on their life. However, healthcare professionals emerged even more highly for negative attitudes when looking at weighted averages. Family, friends and strangers were generally considered to have the least negative impact on respondents' health, but there was less consensus among respondents.

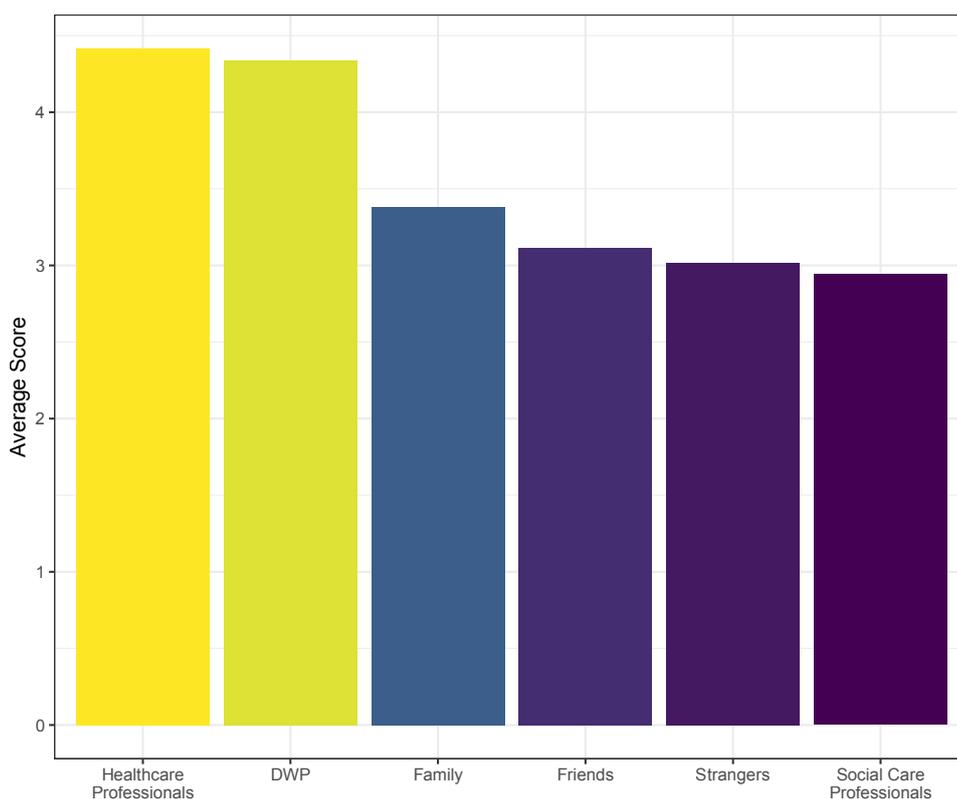


FIGURE 17. Sources of negative attitudes

In contrast, just 1.9% who selected social care professionals' attitudes as having the most negative impact on their life. This may be because many respondents were not receiving social care, or had not applied for it, while many had encountered the benefits system, including PIP, ESA and non-disability benefits. This accords with the findings of other

questions where the benefits system is identified as the most important priority for many respondents.

Although there was not scope within the focus group for a full discussion of policy priorities, the benefit system was a very common theme throughout. When asked to disentangle societal barriers from impairment factors, several participants named the social security system as having a particularly disabling impact on their lives.

Within the focus group, all but three participants had had to stop working as the impact of fluctuating energy limitation made employment unmanageable. The three who were employed faced obstacles such as penalising permitted work rules, lack of support for self-employment, lack of social care support and disability discrimination in the workplace.

The main focus of discussion was the trauma of disability benefit assessments and how this undermined their mental health and well-being. Participants mentioned their distress at having their account of their health dismissed or denied in assessment reports, the gruelling process of appealing wrongful decisions and the general insecurity in their daily lives of not knowing when the next 'brown envelope', triggering the next phase of assessment, would appear on their doorstep.

One participant spoke of her attempts to take on small hours of work that she could manage within her energy limitations and how DWP rules of conditionality prevented her from doing so. Another said that her quality of life would be much greater if society made better provision for people who are unable to work:

What I would really like is to be able to live the life I'm living now but without constant stress due to the financial implications of me not working.

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A third replied that for our lives to be valued and supported would require much broader social transformation in values towards health, illness and disability:

But to alter attitudes would require a complete ideological shift in common thinking around health and what constitutes a 'worthwhile' existence... We live in a very individualistic society and tend to see change as something people do on their own and that illness is a very personal battle. How you change the attitude from the 'personal' to something that has wider application is difficult to imagine.

We wanted to find out which, out of a range of social problems potentially affecting disabled people, had the greatest impact on the lives of survey respondents. Social isolation, social exclusion and stigma were felt to be the biggest social issues affecting the lives of survey respondents. Lack of help and support in daily life was a significant problem. Disability discrimination and, surprisingly, poverty, were rated the least important issues (see Figure 18). Lastly, we asked which values were important to respondents when thinking about improving their quality of life. We used the Keys to Citizenship model to give a range of options for universally-important principles for citizenship and wellbeing (Duffy, 2006). These principles can be summed up as a sense of purpose ("having a sense of meaning or purpose"), control ("the ability to make my own decisions"), money ("having enough resources to pursue my goals"), home ("having a home where I truly belong"), self-directed support ("getting assistance in ways that enable me"), social participation ("being able to live a full life and contribute to society") and quality of social relationships ("having relationships of love"). "Having a sense of meaning and purpose" and "having relationships of love" were the most important values. "Getting assistance in ways that enable me" was the least important value (see Figure 19).

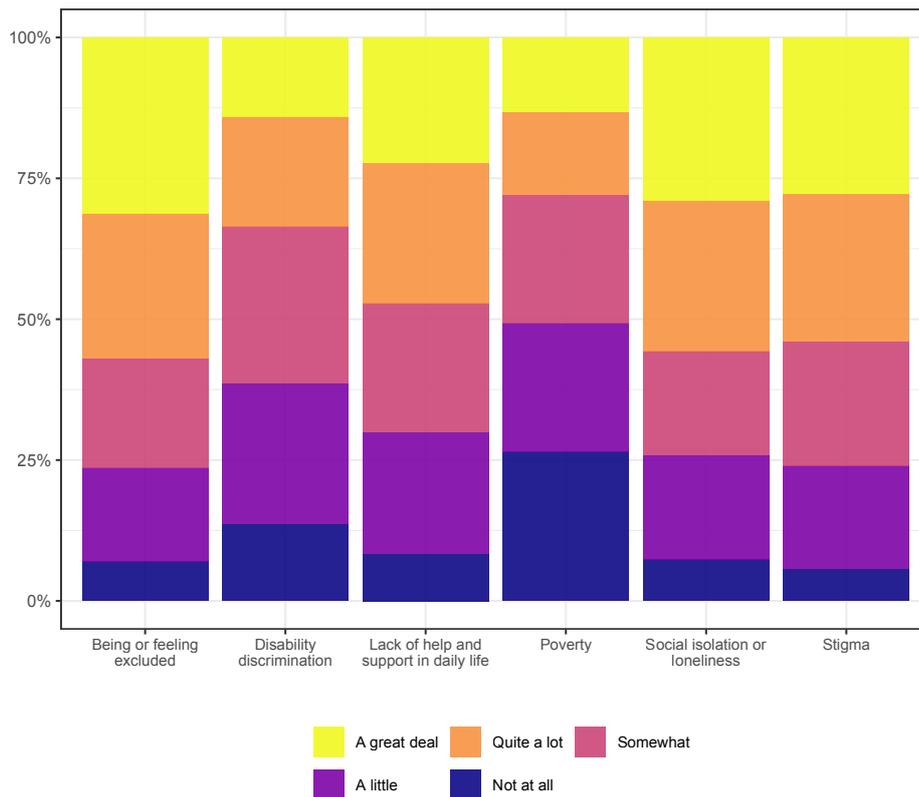


FIGURE 18. Social issues with chronic illness

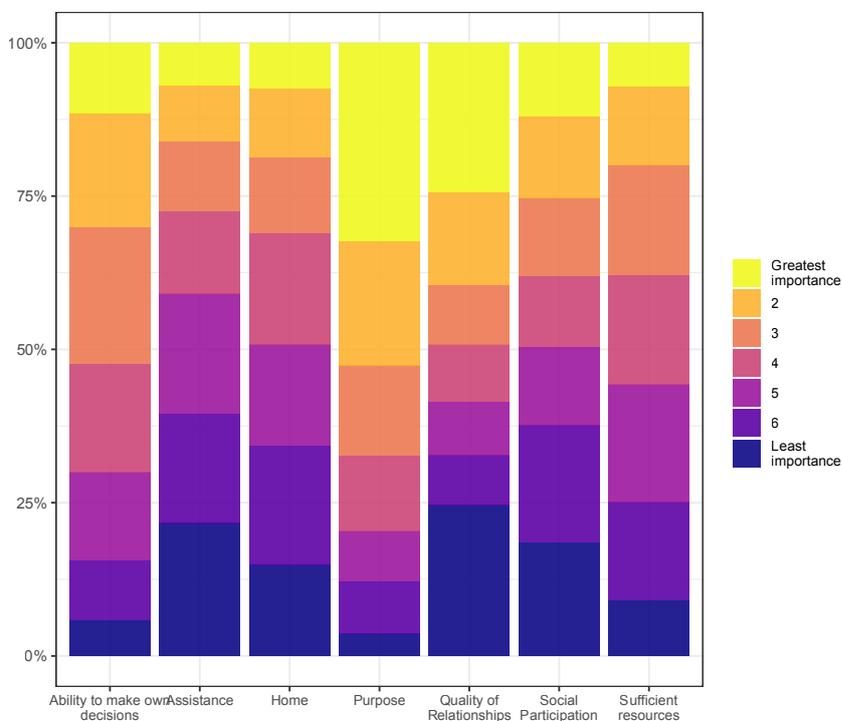


FIGURE 19. Values with chronic illness and 7 Keys to Citizenship

Discussion

The high demand for places in our focus group, the enthusiasm and commitment of participants, and the volume of survey responses demonstrates the strength of support for our agenda. We conclude that the CIIP addressed a gap in the landscape of representation for disabled people with chronic illness in the UK.

The terms ‘long-term health condition’ and ‘fluctuating condition’ are inadequate in conveying the lived experience of impairment with chronic illness. The lexicon of the DPM, the disability sector and disability rights must be expanded to include and describe the experiences and support needs of people with chronic illness. We propose the terms ELCI and ‘energy impairment’. ELCI most closely mirrors language of self-identification, and captures the experience of the group which we were studying, which is people whose illness generates interlinked physical fatigue, cognitive fatigue and pain alongside other illness symptoms.

‘Energy impairment’ also appears to have broad acceptance as a term among people with ELCI, but as a term that relates to fatigue (which people with other conditions may also experience) not illness (which is the defining feature of our study participants). By including other groups of disabled people who may not identify as having chronic illness, energy impairment may help to bridge the divide between chronic illness and disability.

Survey respondents gave clear indications of what future involvement and advocacy work for people with ELCI and energy impairment should focus on. The following is a summary of their priority issues.

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Social security

Social security policy, including Personal Independence Payments to meet the extra costs of disability, is a very high priority for people with ELCI. Our research suggests that having income security is second only to effective healthcare for living as well as possible with chronic illness, and that overturning oppressive attitudes of invalidation and disbelief towards people with chronic illness within the benefit system would improve our quality of life. The social security system for people excluded from mainstream employment by ELCI should be enabling of activity which provides meaning and purpose to people’s lives, even if outside of the formal labour market (Hale 2019, Benstead 2019). The CIIP has already begun research and engagement with policy makers into what an enabling social security system for people with ELCI would look like.

Healthcare

The biggest policy priority area, healthcare, poses a different challenge. The DPM has traditionally excluded medicine and healthcare from the arena of disability activism. Investigating the area of healthcare and medicine within a social model of disability is, therefore, particularly challenging.

The CIIP drew participants together not on the basis of specific diseases, conditions and diagnoses, but on the basis of sharing lived experience of impairment with chronic illness. There are many existing organisations advocating for better medical research and treatment on behalf of specific disease communities. However, what participants shared, regardless of diagnosis, was the experience of being disbelieved, invalidated and dismissed by healthcare professionals because their energy impairment or other illness

symptoms could not be visualised by medical technology. The misfit between lived experience of illness and biomarkers of disease is known as ‘medical uncertainty’.

Anecdotal evidence from the online chronic illness community (based on informal analysis of the #DoctorsareDickheads #medtrauma #medicalabuse platforms on Twitter) suggests that seeking medical help and treatment for problems that cannot be medically verified produces distressing encounters with the professionals concerned.

Overall, survey respondents rated the negative attitudes of healthcare professionals as having the biggest impact on their lives. Further research is needed to explore the impact of medical uncertainty in healthcare encounters and its relationship with ableism.

Social isolation and loneliness

Our research strongly indicates that social isolation and loneliness are among the most pressing problems for people with ELCI. It appears to have at least two dimensions: the loss of social participation through work, and confinement to home, leads to reduced face-to-face interaction; while the lack of understanding of energy impairment, with the consequent invalidation and disbelief, leads to emotional isolation and loneliness. Social isolation and exclusion were rated as bigger problems than poverty or disability discrimination, and having positive, loving relationships was rated as more important than money or housing for wellbeing.

Independent living

The low priority given to issues of independent living by our respondents is noteworthy, given that these are at the heart of the DPM. Social care policy, choice and control over support and Direct Payments all ranked at, or near, the bottom of importance for respondents. The attitudes of social care professionals were also near the bottom in terms of impact on their lives.

This finding should be interrogated further. Most respondents and participants rated their activity restriction due to their health condition as being “a lot”, rather than “a little”. We found strong evidence of mobility restriction, cognitive limitations and social isolation among participants. Lack of help and support in daily life was “a great deal” of a problem for 22% of respondents and “quite a lot” of a problem for a further 25%. Therefore, we should not interpret this finding as evidence of lack of need for care and support with daily living. It is possible that most survey respondents were not in receipt of statutory care and support, and may not have even engaged with the social care system. More research is needed to find out the experiences of people with ELCI in relation to the social care system.

Recommendations

1. Foundations, funders and charitable organisations should support the establishment and sustainability of a user-led organisation (ULO) for people with energy limiting chronic illness (ELCI). The aim of a ULO should be:
 - ◆ Capturing our knowledge and amplifying our voice;
 - ◆ Involving us in the design of policies and services;
 - ◆ Encouraging take up of the terms ELCI and ‘energy impairment’ as strategies for self-advocacy in claiming our rights as disabled people;
 - ◆ The development of information and training on ELCI and energy impairment to increase our access, inclusion and entitlements as disabled people; and
 - ◆ The development of a dialogue between the chronic illness community and the DPM.
2. The DPM and the disability sector generally should engage with the knowledge and experiences of people with chronic illness, and support our language of self-identification. They should adopt the terms ELCI and energy impairment to include us alongside other impairment groups.
3. The ONS should review the language for the category of ‘stamina, breathing, fatigue’ for use in social surveys on disability, in the light of participants’ dissatisfaction with the term ‘fatigue’ and objections to the term ‘stamina’ and in consideration of the fact that energy impairment affects a much broader group than respiratory disease.

CONCLUSION

The Chronic Illness Inclusion Project evolved from the researchers' participation in online networks and grassroots communities for people living with chronic illness. It was motivated by the desire to bring the hidden knowledge and experiences shared within these communities closer to centres of decision making and power over our lives.

The CIIP was inspired by the tradition of emancipatory disability research and sought to explore the potential of applying the social model of disability to the experience of chronic illness. Our key research questions were: What are our shared experiences of a) impairment, i.e. the impact of a health condition on day to day life and b) disability, i.e. the way social structures and cultural attitudes to chronic illness constrain our lives and wellbeing? How can we form a more effective advocacy movement? What are our priorities for collective action for social change?

We analysed the research data according to the following themes: the lived experience of chronic illness; chronic illness and disability/disabled identity; motivations for a chronic illness advocacy movement and policy priorities for improving our lives. For each of these themes we developed associated recommendations for policy actors, civil society including the DPM, and ourselves as we think about what a future advocacy movement might look like.

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Reframing chronic illness as energy impairment?

The main strategy we propose for a future advocacy movement is the reframing of 'chronic illness' into 'energy impairment', or energy limiting chronic illness (ELCI). We found that 'energy impairment' is the term that best captures the most common and the most restricting aspect of a wide range of diseases and comorbidities. It is far from a perfect fit for everyone with chronic illness. It cannot capture individual constellations of symptoms with systemic disease, or their shifting over time. For some people, and in some moments, pain may be paramount, or dizziness, or bowel problems, for example, rather than fatigue. But energy impairment is an abstraction that describes the overall impact of diverse and fluctuating symptoms on function and on activity for a large group of disabled people who are otherwise invisible as a group.

We believe the concept of energy impairment could be crucial as a tool for lobbying policy makers and politicians. It enables them to see us as the second largest group of disabled people in the UK. It enables us to convey what our day to day life and our difficulties are, and to demand policies and decisions that address our needs. If this language is adopted by the chronic illness community, promoted by the DPM and accepted by policy makers this could be a key to improving our quality of life as disabled people.

Chronic illness and the social model

What can we conclude about the value of social model as a tool for developing an advocacy movement for ELCI? As a theory of disability, the social model is overwhelmingly rejected by people with ELCI. The idea that disability is not in our bodies but outside of them feels, not only jarringly wrong, but it can be received as a denial of our embodied experience.

The suppression of illness and impairment experiences within the DPM in the name of the social model has had the (mostly unintended) effect of marginalising the chronic illness community. When we talk publicly about pain, restriction, exhaustion and suffering, we are not welcomed into the DPM.

However, our research has shown that we cannot develop an emancipatory framework for people with chronic illness without first articulating our lived experience of impairment. This is because the social oppression and hostility we experience is rooted in the very denial, dismissal or disbelief of this experience. To resist and challenge this oppression means to affirm our embodied reality.

Our research has also shown that while all disabled people encounter oppression, the nature of that oppression can vary enormously depending on what our impairment is. Our participants highlighted how the disbelief, denial and dismissal of energy impairment produces an experience of invalidation. Our analysis demonstrates that invalidation is highly disabling, both in terms of internalised oppression and accessing our rights as disabled people. It prevents us from asserting our status as disabled people. Yet discussion of invalidation rarely comes within the scope of scholarship on disability and ableism, or disability activism.

This means if we cannot articulate and affirm our impairment we cannot develop an understanding of ableism in its broadest sense.

This does not mean we reject the social model as a rallying cry for transforming the lives of disabled people with chronic illness. Indeed, in many ways, the CIIP has been developing a social model of chronic illness. Our participatory research enabled participants to identify the social stereotypes and cultural attitudes around disability that restricted their lives and their wellbeing. They developed an understanding that stigma and shame comes from outside them and a desire to come together to challenge it.

By forging a collective identity based on our shared experiences rather than on diagnostic labels, we are, in our own way, challenging the medical model of chronic illness. We reject the arbitrariness of medical classification schemes and the hierarchy of diseases according to how much science has discovered about them. Medical knowledge is, largely, knowledge produced about us without us. By articulating and affirming our embodied experiences we are directly challenging the power that it has over our lives. That is surely the very essence of the social model of disability.

The CIIP addressed a gap in the landscape of representation for disabled people with ELCI and energy impairment in the UK. The overwhelming response of our participants and supporters demonstrates the need for an organised movement for change, focussing not on the medical aspects of discrete conditions but on our shared experiences of impairment and ableism.

Our forthcoming manifesto aims to instigate transformative change for people with ELCI and energy impairment. It stems from the overwhelming agreement among CIIP research participants that their lives would improve if there were greater social

understanding and acceptance of ELCI and more respect for and validation of people who live with it.

We must now find a way to build on the foundation laid by all who have participated in and supported the first steps of this new movement.

Recommendations for further research

Further analysis of CIIP survey data is needed to identify sub-groups based on diagnosis, symptoms clusters, degree of activity restriction and policy priorities. This would enable more accurate delineation of ELCI as a discrete impairment group.

The concept of energy impairment should be developed into a spectrum from mild to very severe based on impact on day to day life. This would ensure that all points on the spectrum are included in advocacy efforts and enable better understanding of the range of needs among people with ELCI.

Additionally, our findings indicate the need for further research into:

- The extent and impact of cognitive impairment on people with ELCI, especially in the context of work capability;
- Experiences of employment and interacting with the social security system;
- Encounters between people with ELCI and healthcare professionals, especially in the context of medical uncertainty and contested illness;
- The basis of social isolation and loneliness among people with ELCI and solutions for enabling social connection and improve the quality of relationships;
- Experiences of navigating the social care system.

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APPENDICES



Appendix 1. Project activities

From April 2017 to December 2019 our project activities, other than qualitative and quantitative research, included:

Community engagement

By developing an online presence via a website, blog series, social media platforms (Twitter and Facebook) and regular email newsletter to project followers, we actively engaged with the online chronic illness community throughout the project. Our mailing list of project followers exceeded 1,300 by the end of the project period.

Representation and engagement

We engaged with the Department for Work and Pensions; Shadow Cabinet members (on reform of the social security system); the Shaw Trust; Government Statistical Services and research based at the London School of Economics (on improving disabled people's pay and employment (Sayce, 2018)). The CIIP was involved in the Commission on the Future of Social Security led by Experts by Experience.

For more information on our advocacy and engagement work visit our website:

<https://inclusionproject.org.uk/>

Manifesto

Collaboration on our manifesto, *Resisting Invisibility, Challenging Disbelief*, took place throughout 2019 among the CIIP Advisory Group. A consultation on the proposed manifesto took place among selected stakeholders, including focus group participants and members of the disability rights movement, as well as the chronic illness movement in the UK.

Appendix 2. Sampling method

Thanks to our social media presence and mailing list, we attracted 150 prospective participants from one recruitment email, enabling us to select a sample of 25 people from these volunteers based on their responses to a recruitment questionnaire.

We selected for a range of diagnoses, severity of activity restriction, sex and age (between 18 and 64). We used the Bell Disability Scale (see Appendix 3) in our recruitment questionnaire. This enabled us to select a balanced proportion of people with “severe” (10 – 30% function), “moderate” (40 – 50% function) and “mild” (60% function and above) functional limitation.

Table 3 overleaf categorises the conditions that our participants had, following the International Classification of Diseases (ICD Version 10) by the WHO. The biggest ICD category included musculoskeletal conditions, mental and behavioural disorders and neurological diseases. All the mental health conditions listed were comorbid with physical health conditions.

ICD Group	Total in Group	Diagnosis	N
Certain infectious and parasitic diseases	1	HIV	1
Neoplasms	1	Cancer	1
Diseases of the blood and blood-forming organs	3	Sarcoidosis	1
		Anaemia	2
Endocrine, nutritional and metabolic diseases	5	Cystic fibrosis	1
		Thyroid	2
		Type 2 Diabetes	2
		Poly-cystic ovaries	1
Mental and behavioural disorders	17	Depression	11
		Anxiety	7
		PTSD	2
		OCD (pure O)	1
		Asperger's	1
		BPD	1
		Personality disorder	1
		Dyspraxia	2
		FND	1
		Seizure (dissociative/non-epileptic)	1
Erectile dysfunction	1		
Diseases of the nervous system	15	ME	9
		Chronic fatigue	2
		CSF leak	1
		Peripheral neuropathy	1
		Migraine	3
		Epilepsy	1
		Parkinson's	1
		Nerve root impingement	1
		Sleep apnoea	1
Diseases of the ear and mastoid process	2	Hard of hearing	2
Diseases of the circulatory system	3	Pulmonary hypertension	2
		Pulmonary stenosis	1
Diseases of the respiratory system	3	Asthma	2
		COPD	1

Diseases of the digestive system	2	Chronic liver disease Ulcerative colitis	1 1
Diseases of the musculoskeletal system and connective tissue	15	Hypermobility Syndrome Ankylosing spondylitis Scoliosis Degenerative disc disease Prolapsed discs Displaced L4/L5 vertebrae Rheumatoid arthritis Osteoarthritis Osteoporosis Systemic lupus Sicca syndrome Lower back pain	4 1 1 1 1 1 2 1 1 1 2 1
Diseases of the genitourinary system	5	Chronic liver disease Female problems	1 2
Congenital malformations, deformations and chromosomal abnormalities	2	Congenital vertical talus Ehlers-Danlos Syndrome	1 1
No ICD-10 code – immune-related	4	Idiopathic angioedema MBL deficiency Mast Cell Activation Syndrome Neurochemical disorder	1 1 1 1
No ICD-10 code – other	4	Postural Tachycardia syndrome SIBO	3 1

TABLE 3. Self-reported conditions of focus group participants classified by ICD10 codes

Appendix 3. Bell fatigue scale

The Bell Fatigue Scale (<http://www.oiresource.com/cfsscale.htm>) is a scale of functional impairment developed to measure the impact of fatigue and pain found in ME/CFS.

100: No symptoms at rest; no symptoms with exercise; normal overall activity level; able to work full-time without difficulty.

90: No symptoms at rest; mild symptoms with activity; normal overall activity level; able to work full-time without difficulty.

80: Mild symptoms at rest; symptoms worsened by exertion; minimal activity restriction noted for activities requiring exertion only; able to work full-time with difficulty in jobs requiring exertion.

70: Mild symptoms at rest; some daily activity limitation clearly noted. Overall functioning close to 90% of expected except for activities requiring exertion. Able to work full-time with difficulty.

60: Mild to moderate symptoms at rest; daily activity limitation clearly noted. Overall functioning 70%-90%. Unable to work full-time in jobs requiring physical labour, but able to work full-time in light activity if hours flexible.

50: Moderate symptoms at rest. Moderate to severe symptoms with exercise or activity; overall activity level reduced to 70% of expected. Unable to perform strenuous duties, but able to perform light duty or desk work 4-5 hours a day, but requires rest periods.

40: Moderate symptoms at rest. Moderate to severe symptoms with exercise or activity; overall activity level reduced to 50%-70% of expected. Not confined to house. Unable to perform strenuous duties; able to perform light duty or desk work 3-4 hours a day, but requires rest periods.

30: Moderate to severe symptoms at rest. Severe symptoms with any exercise; overall activity level reduced to 50% of expected. Usually confined to house. Unable to perform any strenuous tasks. Able to perform desk work 2-3 hours a day, but requires rest periods.

20: Moderate to severe symptoms at rest. Unable to perform strenuous activity; overall activity 30%-50% of expected. Unable to leave house except rarely; confined to bed most of day; unable to concentrate for more than 1 hour a day.

10: Severe symptoms at rest; bedridden the majority of the time. No travel outside of the house. Marked cognitive symptoms preventing concentration.

0: Severe symptoms on a continuous basis; bedridden constantly; unable to care for self.

Appendix 4. Schedule of focus group questions

1. Introduction

Hello and welcome to the first week of the focus group. Thank you for your patience in getting to this point. For this first week we would like everyone to introduce themselves so we can get to know each other a little as we embark on this journey together. We would like you to tell us a bit about yourself and why you volunteered to be part of this research.

As part of this exercise, we would like you to answer the question:

Would you use the term "disabled" in thinking about yourself or in describing yourself to other people? If not, why not?

We look forward to finding out a bit more about you.

(Remember, you will need to post your reply first before you can see anyone else's reply. Then we hope you'll be able to come back and read other people's posts and join in discussions. If you're not sure how to answer the question, don't worry, just ask us to clarify in the response box. There's no right or wrong answer!)

2. Chronic illness: What do we have in common?

We all have different diagnoses and may belong to different patient communities. Yet everyone in this focus group wants to make life better for people with "chronic illness". That suggests there are a common set of experiences and issues that unite us beyond our specific diseases or health conditions.

This week we want to try and identify what that common experience is. That will help us develop a language that unites us, and allows us to be heard as a group that is broader than our individual diseases.

Last week we started to share experiences of fatigue, pain, brain fog, unpredictability, and there was also some common ground around how society responds to us when we say we're Disabled. This week we'll keep talking about the impact of your condition on your life through the following questions.

There are 3 questions this week (2a, 2b and 2c) and you can answer one, two, or all of them. If a question seems not relevant to you, you can skip to the next one. [Nb you have to scroll down and click the 'continue to next topic' button to see the next questions]

- a. If you are active on social media, have you come across the hashtag #chronicillness? What does it mean (if anything) to you, and do you use it as a way of finding or reaching out to others? (eg is it about symptoms, about day to day life, about how we're treated by others?)
- b. Have you heard of "spoon theory" or the term "spoonie"? (You can read about it here <https://butyoudontlooksick.com/articles/written-by-christine/the-spoon-theory/> or open the attachment. Does it make sense of your experience?
- c. As researchers, we have both been thinking hard about what language to use to represent our shared experience of chronic illness. We're looking for a term that isn't specific to one symptom, such as pain, fatigue or nausea, but conveys something broader about the impact of symptoms on our ability to function. It also needs to be a term that is easily grasped by policy makers, other disabled people, and society in general. For these purposes, "spoonie" isn't the easiest term for people to understand.

Before we share our ideas, we'd like to hear yours! Do you have any ideas for words or phrases that could represent the impact of chronic illness, as you and others experience it?

3. Exploring disability and disablism

Hello again and thank you for your extra input with the poll last week. Fascinating results! Onto a new topic today: the Social Model of Disability. This is the final topic covering concepts. After this topic we will start talking about the actual social changes we want to see.

First, a brief introduction; the Disabled People's Movement in the UK makes a distinction between "impairment" - a medical condition or differently functioning body or mind, and "disability" - a form of social oppression towards people with impairments which places unnecessary restrictions on our lives. The distinction between impairment and disability is the basis of the Social Model of Disability.

In other words, disability is imposed on top of our impairments, not because of our impairments. The term "disablism" works like the terms "racism" or "sexism". It is also sometimes called "ableism".

We're interested in what you think about this distinction between impairment and disability and exploring disablism/ableism with chronic illness.

Some people think there are two types of disablism: 1. restrictions to doing or activity (barriers on the 'outside'), and 2. restrictions to being, thoughts or emotions (barriers on the 'inside').

If possible, please open the attached document which gives excerpts, a video and a cartoon to illustrate how some disability theorists and activists have discussed disability. These ideas are broadly referred to as the Social Model of disability.

Then answer the following 3 questions:

1. Can you give an example of when you face restrictions to activities or participation which are caused by external factors, not by your health condition? You might consider restrictions caused by the environment, people's attitudes or lack of awareness, the way activities are organised.
2. Can you give an example of when society's response to your condition creates negative thoughts or emotions in you? You might have negative thoughts or emotions arising directly from your impairment/health condition and its impact on your life. But there may be some other negative thoughts or feelings that come from the outside - from the way people view you or treat you. Although it may be hard to separate the two, it can be a useful exercise in campaigning for social change.
3. What do you think about this distinction between impairment and disability? Is it helpful to you?

Appendix 5. Analysis of diagnoses reported in survey

Frequency and spread of medical conditions

Respondents were asked to list their health condition(s) in a free text box. Respondents listed an average of 3.45 conditions each. Analysis and classification of this data identified approximately 700 discrete health conditions or diseases. Almost half (340) of listed conditions were reported only once, and that number would be much higher if each kind of cancer were listed separately. The categories of Myalgic Encephalomyelitis, ME/CFS and Chronic Fatigue Syndrome were listed separately. There is strong opinion in the patient community that ME and CFS are distinct conditions although the NHS conflates them.



FIGURE 20. Correlation of frequently reported conditions

About the Authors

Catherine Hale founded the Chronic Illness Inclusion Project and was lead researcher for this report. She previously conducted independent research into disabled people's experiences of social security, labour market policy and social care, authoring reports for Mind, Action for ME, Inclusion London and the Spartacus Network. Catherine is a member of the Independent Living Strategy Group, and the Commission on Social Security led by Experts by Experience. She has also advised on projects with Shaping Our Lives and the Joseph Rowntree Foundation and been active with MEAction UK and in local disability campaigns in Lewisham, London.

Catherine studied Social Anthropology as an undergraduate and PhD student at the London School of Economics. She has lived with ELCI, ranging from moderate to very severe/completely bedbound for over 30 years.

Stef Benstead is an independent researcher in disability and social policy. She has worked with Ekklesia and the Spartacus Network and is currently working with the Chronic Illness Inclusion Project and Church Action on Poverty.

Stef is the author of *Second Class Citizens: The treatment of disabled people in austerity Britain* (2019) describing the impact of austerity, neoliberal ideology and welfare myths on sick and disabled people.

Jenny Lyus was Co-Investigator on the Chronic Illness Inclusion Project until summer 2018 and is now an Advisory Group member for the project. Jenny's passion for positive social change is focused on efforts to amplify the voice of people who live with Energy Limiting Chronic Illness. She is interested in building on ideas such as the Social Model of Disability and the 'Spoon Theory' to find more effective ways to represent the unheard and unmet needs of this community, both within the Disability Rights Movement and wider society.

During her 22 years lived experience of fluctuating energy impairment, Jenny has worked with other disabled people in a variety of settings both paid and unpaid. She has had project management style roles in Action on Disability and Work UK (formerly the Vassall Centre Trust) and disabled children's charity Time2Share. In recent years she has been using her available energy to campaign for better quality, better funded ME research and against inappropriate clinical guidelines, as a NICE rep for #MEAction UK and in the stopGET campaign.

Evan Odell is a researcher at disability-led organisation Disability Rights UK, where he undertakes original quantitative and qualitative research. Evan completed an undergraduate degree in Political Science at Laurentian University and the University of British Columbia, and an MSc in Comparative Social Policy at the University of Oxford.

Evan's research covers an array of issues, including social attitudes to disability and disabled people, the welfare state, theoretical approaches to health and disability, open source research software, and text-as-data. He is a member of the Royal Statistical Society and a Fellow of the RSA.

Anna Ruddock edited a blog series about chronic illness and academia for The Sociological Review in 2018. She joined the Chronic Illness Inclusion Project Advisory Group at around the same time. Anna has a PhD in medical anthropology from King's College London and is finishing a book about the association between medical education and health inequalities in India.

As a person with ELCI, Anna found the demands of academia increasingly disabling, so she left. She currently works for Sightsavers on a part-time basis, where she co-leads the organisation's work to ensure that research evidence informs its global programming for disability inclusion. Anna has had M.E. since 1996.

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Or find us on Facebook here: [centreforwelfarereform](https://www.facebook.com/centreforwelfarereform).

Chronic Illness Inclusion Project

The Chronic Illness Inclusion Project (CIIP) has been running since 2017 and is currently seeking funding to continue its research.

Read more about the CIIP at: www.inclusionproject.org.uk

To find out more contact the CIIP's Director, Catherine Hale via email: catherine.hale@citizen-network.org

Relevant Publications



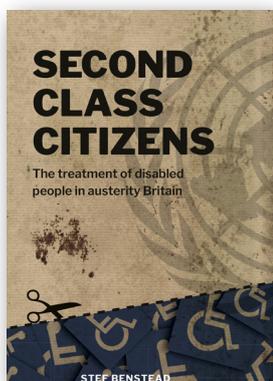
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An exploration of the meaning of the term ‘chronic illness’ and the relationship between people with chronic illness and the disability movement.



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