



Reclaiming 'Chronic Illness'

An introduction to the Chronic Illness Inclusion Project

A DISCUSSION PAPER FROM THE CENTRE FOR WELFARE REFORM

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CHRONIC ILLNESS
INCLUSION PROJECT



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Foreword

I must admit that I had no understanding of the reality, severity and widespread nature of chronic illness until very recently. It was only as we began our own efforts to combat the UK austerity programme, which began in 2010, that we discovered that many of those people we were fighting beside were people with a chronic illness. And, it was only by listening to their experiences that I understood that there were layers of injustice that I had never truly appreciated.

Today, as then, people with disabilities face the most severe cuts in support and income of any group of UK citizens. Disabled people also face severe prejudice, which ranges from systemic injustices that keep people in poverty and exclude them from a life of citizenship to hate crime and social isolation. Countries like the UK claim to be civilised and to have a positive attitude towards disabled people; but the reality is very different.

What makes these challenges even more negative is the failure of the disability movement to come together a united movement for change. People with learning disabilities, people with mental health problems, older people and people with chronic illness - all very large groups - either don't see themselves as part of the disability movement or are effectively excluded from it. Nobody is to blame for this. Oppressed groups often fragment in this way. But this fragmentation is a serious source of weakness.

This is what makes the work of Catherine Hale and her colleagues so inspiring. The *Chronic Illness Inclusion Project* marks a serious effort to think socially and politically about what it means to be a person with a chronic illness. It is not an attempt to simplify things or to force people to conceptualise their situation in one particular way; but it is an effort to think about the similarities and differences between different and connected forms of injustice. It is an effort to look with hope at the kind of society we should want to be, and to treat people with chronic illness as agents of change, as campaigners and as researchers in their own experience.

The Centre for Welfare Reform is a small organisation which is designed to give voice to those who are excluded from mainstream policy-making and influence. I am honoured that so many people with chronic illness have become Fellows of the Centre and have used the Centre to share their research, experiences and proposals. I am thankful also to the National Lottery funded DRILL programme for being generous enough to include the Centre and people with chronic illness, in its grants programme. We hope that we can seize this opportunity to help overturn the injustices we all face.

Simon Duffy

Director of the Centre for Welfare Reform

Summary

This discussion paper presents the ideas and assumptions behind the *Chronic Illness Inclusion Project (CIIP)*, part of the DRILL programme of disability research.¹

My own immersion in online networks of activism and solidarity lead me to give a particular slant to the term 'chronic illness', a meaning which is perhaps not universally shared. For me and fellow researchers in the *CIIP*, having chronic illness means being a 'spoonie', that is, having very limited units of energy that must be carefully rationed.

A key aim of the *CIIP* is to translate our experience of chronic illness into the social model of disability, beginning with the distinction between impairment and disability. In this paper, I argue that, 'chronic illness' is a self-ascribed identity which implies both a distinctive form of impairment (in our case, bodily malfunction) and a shared experience of disability or disablism (social oppression).

Chapter 2 of this paper outlines the concept of limited energy and systemic impairment and proposes the term 'stamina impairment' to capture the lived experience of chronic illness.

Chapter 3 suggests that the oppression faced by people who identify as having chronic illness is based on the invisibility of impairment and the unequal relationship between lived experience of our bodies and scientific medical knowledge on illness and disease.

Chapter 4 suggests that chronic illness is a hidden impairment group on the margins of the UK *Disabled People's Movement (DPM)* and unaccounted for in social and public policy. It explores the historical and ideological reasons for this marginalisation and proposes that exploring a social model of chronic illness through emancipatory research will help to forge a closer and mutually-beneficial alliance between the *DPM* and the online chronic illness communities, as well as build a platform for social, political and cultural change based, not on medical diagnostic labels, but on shared experiences, needs and aspirations.

I. Introduction

This discussion paper introduces some of the key ideas and assumptions driving our research for the *Chronic Illness Inclusion Project (CIIP)*. Thanks to the innovative DRILL programme of disability research, we have a rare opportunity to follow in the footsteps of the emancipatory disability research tradition (Oliver, 1992; Barnes & Mercer, 1997; Beresford & Wallcraft, 1997) which underpinned the UK *Disabled People's Movement* and its allied movements in the 1990s.

Our research method involves calling upon the collective knowledge of our peers through an extended online focus group, as well as testing the representativeness of this knowledge among a broad supporter base of over 800 people who have answered our call to sign up to the *CIIP* mailing list in order to build a collective voice for people who identify as having chronic illness. By exploring the social model of disability in relation to chronic illness together, we aim to pinpoint the nature of the disablism we experience: the avoidable restrictions placed on our lives and our wellbeing. Through this process, we will co-produce an agenda for social, political and cultural change, with focus group members, as well as with our broader support base.

The ethics of emancipatory disability research requires that researchers not contrive to present themselves as neutral observers of social phenomena, but reveal how their research agenda is influenced by personal experience and informal observations grounded in their everyday life (Vernon, 1997). This is the purpose of publishing a discussion paper prior to embarking on our formal research process.

The purpose of this discussion paper is also to initiate a conversation with all sections of the *Disabled People's Movement* as well as policy makers concerned with disability. As researchers whose impairments prevent us from working and operating within traditional organisational or university settings, disseminating our ideas in this way helps us to overcome the isolation of working on the periphery of traditional institutions and Disabled People's Organisations. We warmly welcome engagement and feedback from disability academics and activists alike, as well as all those working to improve our lives through policy formation.

Engaging with our stakeholders at this point in the project is crucial. For various reasons, the term 'chronic illness' has never been part of the lexicon of the UK *DPM* and has equally little currency in the social policy framework around disability. Therefore, the thrust of this paper is about explaining and justifying my choice and interpretation of 'chronic illness' as the organising theme of our research. In this way, we hope our research

findings will be more widely shared and their implications will have a greater impact.

Personal Background

I am a disabled researcher. I have lived with a diagnosis of myalgic encephalomyelitis (ME) (or 'chronic fatigue syndrome' in common medical parlance) for almost 30 years. It has severely restricted my physical and cognitive activity thresholds and curtailed many, indeed most, forms of participation in society. For about 20 of those years I had little to no knowledge of the social model of disability. I referred to myself as "disabled" only strategically, for administrative purposes. Mostly, I reluctantly labelled myself, when forced to explain my lack of social and economic participation, as 'ill'. I became attracted to the social model of disability as a way of exploring my experience of profound social exclusion within a broader arena than that of the ME patient community. Locating my disadvantage in society's failure to include me and treat me as an equally valuable citizen seemed to offer a more positive identity and liberating outlook. I did not anticipate how difficult it would be to engage with, and feel part of, the *Disabled People's Movement*, either at a local or a national level. Nevertheless, I have now achieved a rewarding sense of belonging and fellowship with other disabled people. I became aware of the online 'spoonie' and 'chronic illness' movements accidentally, through close, online collaboration with fellow welfare activists and researchers. We had different diagnoses, but common experiences of impairment and disability, which we encapsulated using the term 'spoonie' to refer to ourselves. It became apparent to us that our experiences were not well represented, and were sometimes even unwelcome, within the mainstream disability rights movement. I became persuaded that our experiences should be explored and articulated as an important step towards emancipation.

2. What do we mean by 'chronic illness'?

I propose that 'chronic illness' implies both a specific form of impairment and a virtual social movement of solidarity, peer support and resistance against oppression.

This assertion is borne out of my experience and that of my co-researcher and project advisory group. Aside from our role as 'researchers', each of us individually is engaged in informal online platforms for activism and peer support (most commonly Twitter, Facebook and blogs) where 'chronic illness' has commonly-understood meaning and usage. The use of # or hashtagging in social media communication enables people who share sociocultural experiences and perspectives to assemble – especially where 'real life' assembly is difficult or impossible – and promotes discourse and deliberative practices which have the features of social movements.

Our immersion in these virtual networks of communication leads us to assert that chronic illness, and its closely correlated concepts 'spoonie' and 'chronic pain', function as badges of identity for people who share common experiences of:

1. A certain form of impairment
2. A shared experience of disablism, or social marginalisation, based on the nature of our impairments.

While our focus is on the digital chronic illness community as a source of evidence and prospective research participants, it is likely that the knowledge contained online applies to a much larger demographic section of people with chronic illness and not only those who communicate through this form.

'Chronic illness' as a form of impairment

Within Disability Studies, the crucial distinction between 'impairment' and 'disability' underpins the social model of disability. But, for reasons I will explore later, 'illness' is often distinguished from 'impairment' and not incorporated into the social model of disability. Illness remains a state apart from impairment.

I maintain, however, that in its chronic form, illness is not conceptually distinct from impairment. Rather, the state of chronic illness involves impairment of physiological processes that restricts activity and function,

even if the underlying impairment is poorly understood and intangible. For the purposes of our research, I have adopted a working hypothesis that chronic illness refers to a health condition involving significant energy limitation through physiological dysfunction that produces the experiences labelled by medicine as 'fatigue', 'pain' and 'malaise'. In other words, chronic illness entails significant impairment of stamina. This puts the experience of chronic illness in a completely different existential dimension to the pain and fatigue experienced by non-disabled people, or, indeed, by 'healthy' disabled people. This loose definition arises from my informal observation of the way the term chronic illness is used on social media, as well as from an informal poll of project followers. We asked 500 people subscribed to our *Chronic Illness Inclusion Project* mailing list:

Do you agree that chronic illness is energy limiting illness where fatigue and/or pain and brainfog are a very big part of our day to day experience?

95% of 153 respondents agreed with this statement.

Another way of expressing the relationship between chronic illness and impairment is that chronic illness entails global or systemic impairment, often of a fluctuating nature, rather than localised impairment of limbs or senses which is often stable. Very often the precise nature of impairment that leads to the symptom labelled medically as 'fatigue' (for example) is not medically understood or is an emergent field of knowledge (e.g. cellular bioenergetics is impaired in patients with chronic fatigue syndrome (Tomas et al, 2017)).

Moreover, I maintain that impairment of function with chronic illness is both physical and cognitive, cumulative and, to some extent, interchangeable. What this means is that I can do physical activity X (e.g. using the toilet, walking to the post office), but the impact of performing the activity on my functional capacity means I can only do X once or twice in the day, or the week, or the month. Just as importantly, if I do X, then I can't subsequently do a completely different activity (Y), such as a cognitive activity, because all activities draw from the same limited budget of energy.

In practical terms, for someone with severe ME/CFS (Myalgic Encephalomyelitis/Chronic Fatigue Syndrome), for example, on any one day, they may have to choose between brushing their teeth and having a 5-minute conversation with a friend because performing one activity cancels out capacity for the other. This idea is frequently expressed through the concept of rationing. Rather than being categorically 'incapable' of performing certain activities, as the traditional notion of impairment implies, people with chronic illness are restricted by having to tightly ration small units of energy in order to prioritise the activities of material survival.

“As a result of systemic impairment, we are “just bad enough at a large enough number of things to be unable to function in society while still being able to do most of the component tasks to some limited degree.”

Clutton (2017)

The concept of rationing small units of energy is what gave rise to ‘spoon theory’: a popular metaphor for explaining the experience of chronic illness. See Appendix 1 for the background and explanation of the term ‘spoonie’. I propose the term “stamina impairment” to encompass these ideas of global energy limitation.

Demographic features of chronic illness

The chronic illness identity is not limited to any particular disease or illness. Rather, it transcends diagnostic categories to focus on the experience of impairment. Analysis of hashtag trends indicates that the most common conditions associated with both #chronicillness and #spoonie are (see Appendix 2 for an explanation of this hashtag analysis):

- fibromyalgia,
- ME or CFS,
- lupus and chronic pain
- EDS (Ehlers-Danlos Syndrome),
- CRDP (chronic regional pain syndrome),
- POTS (postural orthostatic tachycardia syndrome),
- chronic Lyme Disease,
- Crohn’s disease and
- Irritable Bowel syndromes.

To a lesser extent, rheumatoid arthritis, MS (multiple sclerosis), endometriosis are among other conditions associated conditions.

An important feature of the chronic illness identity is a high degree of comorbidity of physical health conditions, as well as high rates of coexisting mental health problems. A large majority of the 155 respondents to our recruitment survey listed more than one physical health condition, and 51% reported a mental health condition. In addition, I would suggest, from informal observation, that people with long term conditions that can be managed by medical or behavioural intervention, such as diabetes or asthma, and who do not experience significant restriction of activity, do not appear to contribute to chronic illness discourse online. People who

define themselves as having chronic illness seem to experience significantly debilitating fatigue and/or pain despite adherence to pharmaceutical or behavioural treatment regimes. To prospective participants for our research forum, we posed the question:

Do your condition(s) or illness(es) reduce your ability to carry out day-to-day activities?

Out of 153 respondents, 13% said 'Yes, a little', 87% said 'Yes, a lot' and none said 'Not at all'.

This further suggests that people self-describing as having 'chronic illness' are a subset of people with long term health conditions who have significant activity restriction due to stamina impairment.

Many disabled people with stable impairments also experience pain or fatigue, either ongoing or periodic, as a secondary feature of their condition. Whether they identify as having 'chronic illness' may depend on how restrictive their pain or fatigue is, relative to their other impairments. Of course, people may identify as having chronic illness as well as disability resulting from stable impairment.

'Chronic illness' is a self-ascribed identity, emerging spontaneously from online discourse and practices. It is not a label derived from scientific medicine or government administration. In this sense, the incidence and prevalence of stamina impairment remains hidden from policy formulations relating to disabled people. Its closest synonym, 'long term health condition', includes conditions that may not cause significant impairment or activity restriction if they are managed through pharmaceutical or behavioural intervention.

In online chronic illness networks, women vastly outnumber men. 80% of respondents to our recruitment survey for prospective participants were female. This could be due to the fact that there is a much higher incidence of autoimmune disease among women. It could also be that women are more likely than men to be active in social media discussions about chronic illness.

However, the limited evidence available suggests that stamina impairment is the second largest impairment type among disabled people of all age groups. Within the caseload of incapacity benefit claimants, this group could be similar in size to the category of Mental and Behavioural Disorders, often cited as the largest group of in receipt of Employment and Support Allowance (ESA) (see Figures 2 and 3).

The data on disability for the government's *Family Resources Survey* (FRS) includes an impairment category 'stamina/breathing/fatigue' which, while

not mentioning pain, is closely matched with “spoonie” characteristics and differentiates chronic illness from static mobility impairment. According to the FRS, “stamina/breathing/fatigue” is the second largest impairment group among disabled people in the UK after mobility impairment, at 34% for working-age adults and 39% for all age groups (see Figure 1).

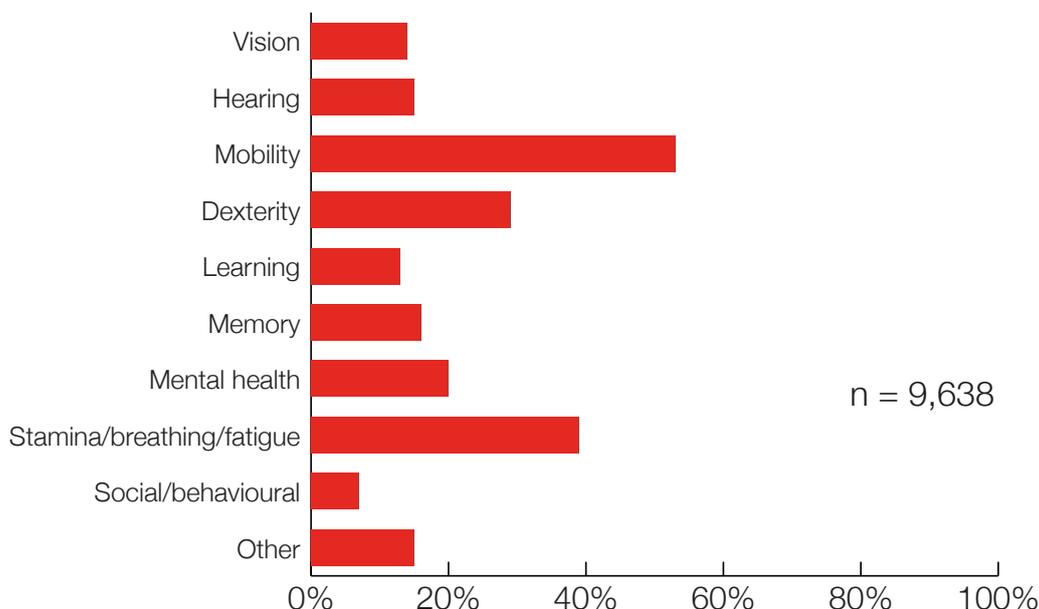


Figure 1. Impairments reported by disabled people, all age groups, 2014/15

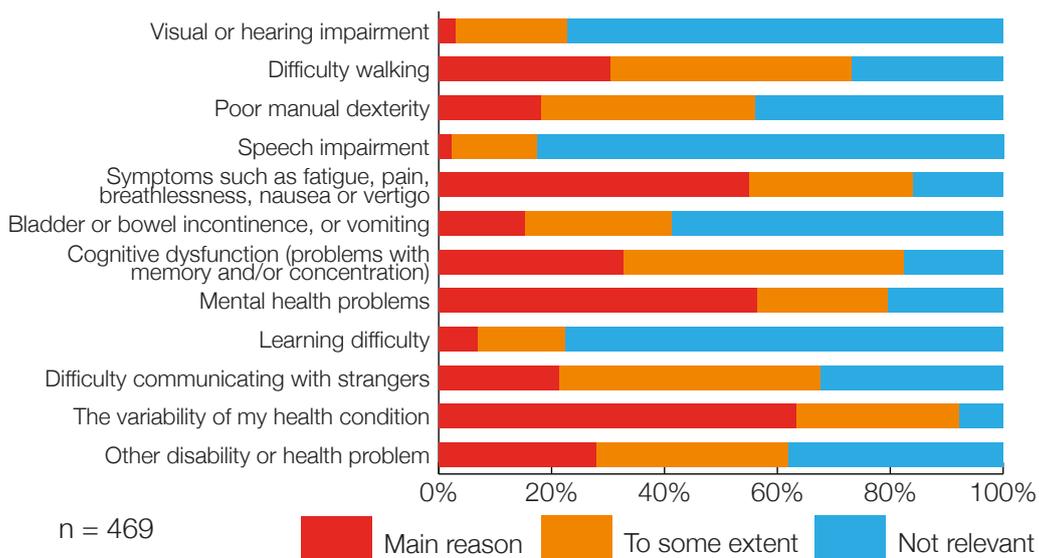


Figure 2. Difficulties or health problems which make it difficult to work

As Figure 2 shows, a convenience survey of 500 ESA claimants in the Work Related Activity Group indicates that, irrespective of diagnosis, 'symptoms such as fatigue, pain, breathlessness, nausea or vertigo' were a main factor in limiting work capability for 55% of respondents while 'mental health problems' were a main factor for 56% (Hale, 2014).

Benstead (2016) obtained very similar findings in a sample of disabled people's views on improving assessment and support systems. The categories are slightly different; pain and fatigue had the biggest impact on work capability (see Figure 3).

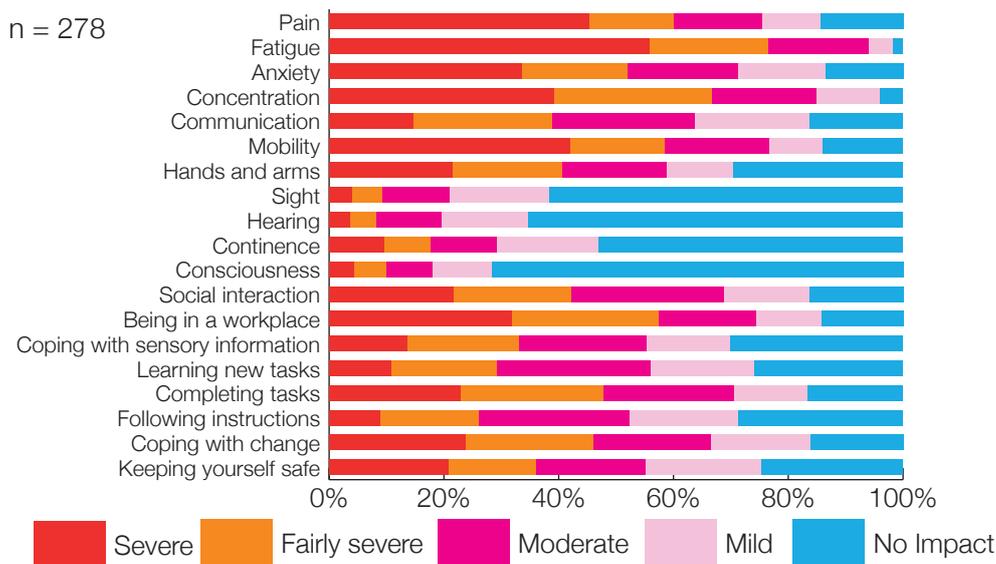


Figure 3. Impact on ability to work by different aspects of health condition

While this data is limited, it suggests that stamina impairment (equivalent to the chronic illness impairment, as I have defined it) is a hidden but large impairment group within the population of disabled people. It is also a large, but hidden proportion of disabled people in receipt of out-of-work disability benefits (and probably other disability benefits such as Personal Independence Payments (PIP), too).

This means our needs are less well articulated and accounted for in policy areas such as welfare benefits, employment support and social care, than other impairment groups.

3. Chronic illness and disability

Doing emancipatory research on chronic illness clearly involves moving beyond descriptions of impairment to considering the social and political aspects of disadvantage. In other words, exploring disability from the perspective of a social model of disability.

Alongside participants in our online focus group, we will be exploring how and why people with chronic illness are marginalised by society, what the relationship is between our impairment and our marginal status, and how this can be understood in the framework of disability, as expressed by the social model of disability, or 'disablism'.

Following Thomas (2010), I understand disablism as:

“The social imposition of avoidable restrictions on the life activities, aspirations and psycho-emotional well-being of people categorised as ‘impaired’ by those deemed ‘normal’. Disablism is social-relational in character and constitutes a form of social oppression in contemporary society.”

Thomas (2010)

Our emancipatory research project will lead to the co-production of a manifesto for social change for people with energy limiting chronic illness. We will be asking how changes in society's response to energy-limiting chronic illness can mitigate some of the disadvantages. In other words, what are the avoidable restrictions on our life activities, aspirations and psycho-emotional wellbeing ('disablism') and how can they be challenged and overcome?

Arguably, the social model has most readily benefitted those disabled people whose impairment is apparent in social interactions and whose disadvantage can be wholly or significantly mediated by social, political and legislative measures such as anti-discrimination legislation, self-directed support, or accessible environments and transport systems. For those whose impairment is not readily apparent to society (and has to be articulated and communicated) and those for whom social and political gains of the movement have not significantly mitigated disadvantage, the benefits are far fewer. This may explain why chronic illness and the social model of disability are not often used in the same sentence.

People in the chronic illness community tend to be socially isolated because stamina impairment renders them effectively housebound and unable to access work, leisure or social activities. There is a certain paradox

in the fact that, according to the social model, the more 'ill' someone is, the less 'disabled' they are:

"An individual with a chronic illness may have periods in which their contact with the social world is curtailed to such an extreme that external restrictions become irrelevant."

Crow (1996)

A crucial question to explore within our online focus group is the extent to which society in general, including employers, civil society organisations and government policies, can, and should, make adjustments to enable participation for people who are wholly or largely housebound by stamina impairment.

Correspondingly, what could inclusion and participation look like when one cannot be physically present in spaces of work, community or political action? These questions have barely begun to be addressed by the *Disabled People's Movement*. In part, this may be because the internet and communication technologies that enable virtual connection and participation between people who are housebound are still too new and too rudimentary to be part of mainstream access provisions. (The recent livestreamed conference on Ableism in Academia is an example of the possibilities of remote access.²) It must also be explained by a lack of awareness of the impact of stamina impairment in its severe form, that is, preventing people leaving their beds or homes. Our very absence from society is largely invisible.

The manifesto resulting from our online focus group will provide some of the answers to these issues. What we already know from existing literature is that, alongside some degree of more or less avoidable physical isolation, people with energy-limiting chronic illness also experience a sense of marginalisation and social disconnection that goes beyond the physical confinement imposed by their impairment. The transgender rabbi Elliot Kukla puts it thus:

"I am used to being rejected and told I should not exist. But nothing prepared me for the outsider status of being chronically ill."

Kukla (2018)

Claudia Gillberg's discussion paper *A Troubling Truth* gives a compelling personal account of this emotional isolation (Gillberg 2016). Gonzalez-Polledo's analysis of chronic pain networks on social media found that within #pain and #spoonie communications on Tumblr the two predominant themes were the difficulty of communicating about pain with

clinicians and significant others, and the difficulty of coping with the effects of this “(ex)communication” (Gonzalez-Polledo, 2016).

Following these scholarly accounts, as well as my familiarity with the chronic illness blogosphere, it appears that social oppression arises from two distinct features of energy-limiting chronic illness:

1. The invisibility and intangibility of stamina impairment.
2. The paucity of medical knowledge and understanding of the physiological mechanisms of ‘fatigue’, ‘pain’ and ‘malaise’ leading to stamina impairment, and the unequal power relationships between doctor and patient in defining and labelling disease and disability.

Invisible illness, inadequate language

There are numerous blog posts and social media discussions listing the most distressing or annoying responses people in the chronic illness community receive from friends, family or acquaintances. Possibly the most common complaint, in my observation, involves the remark, ‘But you don’t look sick.’ Often intended as a compliment, this remark can be experienced as deeply oppressive. I suggest this is because it exposes the major gulf between embodied experience and outward appearance and the fact that embodied knowledge can be so easily dismissed or denied by the casual observer in favour of a cursory appraisal of reality.

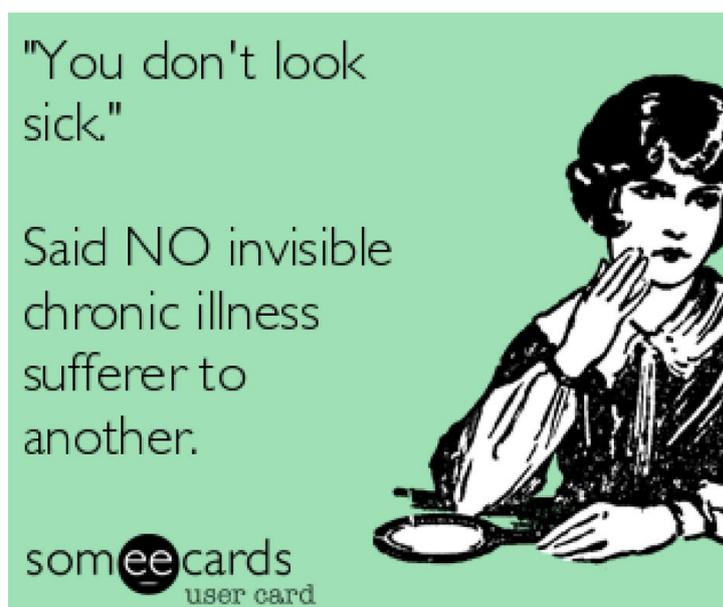


Figure 4. Humour and irony in a social media communication of chronic illness

"I know how you feel". Another frequently expressed complaint on social media networks for #chronicillness is the trivialisation of our impairment through comparison with non-disabled bodily experiences. The stamina impairment we experience is on a completely different scale to the 'pain' and 'fatigue' experienced by non-disabled people, or by 'healthy' disabled people, and yet this different existential dimension is rarely understood and very hard to grasp through language. The very terms 'fatigue', 'pain' and 'malaise' reduce overwhelming and catastrophic physical experiences to a mundane level and erase the distinction between people with impairment and disability and those without.

'I'm tired too, but I have to keep going' is another common refrain made to people with chronic illness. With it comes the implication that activity restriction is a matter of choice that results from an exaggerated behavioural response to common health problems, unconscious malingering, or simple laziness, rather than a consequence of physiological impairment. It is always experienced as a negative moral judgement on the part of the speaker.

The wilderness of 'medically unexplained' illness or symptoms

Some health conditions prevalent in the chronic illness community are the subject of heated debate within medicine regarding their standing as legitimate diseases rooted in pathophysiological processes. Fibromyalgia and ME/CFS have been the classic examples of medically-contested illness (although recent biomedical research is revealing abnormal physiological function in ME). Others, like Ehlers-Danlos Syndrome and Crohn's disease, are medically-accepted diagnoses but can be difficult to diagnose in practice and, therefore, frequently remain 'medically unexplained' for years. Others, like MS and rheumatoid arthritis, are well-defined diseases, however, patients report that fatigue and malaise are the most debilitating aspect of their condition and that these features are dismissed and ignored by medicine in favour of more 'objective' biomarkers of disease.

Whether a condition is medically well-defined or not, what members of chronic illness communities share is that our embodied knowledge of stamina impairment (or lack of "spoons") is not known or mapped by medical science. In recent years, medical science appears to have advanced in its understanding of pain (Gold & Gebhart, 2010). However, a general theory of the mechanisms underlying 'fatigue' remains elusive (Friedberg et al, 2013), possibly because the term fatigue encompasses such heterogenous states.

The American disability scholar Susan Wendell, who lives with ME, analysed how, in Western scientific medical discourse, subjective experiences of pain and fatigue are deemed irrelevant and even unreliable unless they can be correlated with clinical or laboratory findings of physiopathology or disease. Wendell explains how the social and cognitive authority of Western medicine:

“Affects how we experience our bodies and how society describes our experiences, validating or invalidating them... adding the burden of epistemic invalidation to many people’s experiences of illness and disability.”

Wendell (1996)

In feminist terms, typical healthcare encounters follow a ‘paternalistic’ model which “allows for no agency on the patients’ part, elevating healthcare personnel, specifically doctors, to authoritative knowers.” (Gillberg, 2018). Moreover, there are undoubtedly gender issues at play in this power imbalance. Not only are women more likely have symptoms dismissed as psychological in origin but diseases with a higher prevalence among women are more likely to be framed as hysteria (or its modern equivalent, conversion disorder). Wendell noted that, in the field of medical ethics:

“Very little attention has been paid to the dangers of having physical experiences of illness or impairment ignored or invalidated by medicine in societies where medicine has great cognitive and social authority.”

Wendell (1996)

However, in recent years, scholarship in the field of medical ethics has begun to explore this area.

Carel and Kidd (2014) have applied the concept of ‘epistemological injustice’, developed by philosopher Miranda Fricker (Fricker, 2007), to the field of healthcare. They demonstrate how patients’ testimonies of illness can be downgraded as unreliable evidence in a way that diminishes their moral standing as well as their credibility as witnesses to their own bodies. Blease et al. apply this framework to the case of ME/CFS, showing how an ‘epistemic gulf’ between healthcare professionals’ and patients’ understandings of the illness leads to negative stereotyping, reduced credibility and testimonial injustice (Blease et al, 2016).

These authors limit the analysis of ethical injustice in medicine to the context of clinical encounters between doctor and patients and to the impact on access to healthcare for patients with so-called ‘medically unexplained’

symptoms or illness. I suggest that 'epistemological injustice' may be very important subject to explore beyond medical ethics, in the wider framework of Disability Studies. The inequalities of power involved in diagnosing and defining illness and disease can cause rejection, isolation, loneliness and despair. This 'loss of anchoring in communities' (Wendell,1996) must be understood as a form of disablism.

4. Chronic Illness and the UK *Disabled People's Movement*

Disability and disablism were initially explored and articulated largely by scholars and activists who had stable and localised impairment resulting from spinal injury or impairment of senses, for example. In the intervening years, however, user-led movements have emerged for people with other impairments, such as mental health service users, people with learning difficulties and people living with dementia, some of whom even contest the concept of impairment itself. Whilst adopting a social model of disability and the emancipatory goals of the *Disabled People's Movement*, they have felt it necessary to explore their own experiences and define their own agenda for social action and change.

This demonstrates that the nature of social oppression experienced by disabled people is not universal but results from a dynamic relationship between a particular impairment and the way society and culture respond to it, as well as, of course, the interaction with other forms of oppression (e.g. ethnicity, gender or class) experienced by any one individual. Impairment, therefore, cannot be bracketed out from discussions of disability and disablism without imposing a false universalism.

I have argued that the term 'chronic illness' is used on social media to refer to both a lived experience of stamina impairment and a shared experience of disability or disablism. However, for historical and ideological reasons, chronic illness is not included as a unit of analysis in the UK, either within Disability Studies or social policy deliberations concerning disabled people. The impairment of stamina that characterises chronic illness is barely acknowledged or understood. Furthermore, I would suggest that the rejection of 'chronic illness' as a unit of analysis has further contributed to marginalisation of people with chronic illness within society. It is worth exploring how this has come about.

The disappearance of 'chronic illness'

From the 1990s onwards, the UK *Disabled People's Movement* and the emergent discipline of Disability Studies had very valid reasons for rejecting the concept of 'chronic illness'. The study of 'chronic illness and disability' had, until then, been the terrain of non-disabled researchers in the fields of medical sociology and health psychology. It was dominated by interpretative studies of the experience of 'illness', which focused on individual coping

mechanisms, including the management of 'stigma' and other perceived threats to 'self' and 'identity' (Barnes & Mercer, 1997).

Even when sympathetic to its subjects and intending to help people adapt to chronic illness and impairment, the study of 'chronic illness' conformed to a social deviance paradigm of disability (Thomas, 2012; Barnes, 2012). Embedded in the study of 'chronic illness' was a hierarchical relationship between the knowledge produced by professional researchers and that of their research subjects waiting to be elucidated.

The discipline of Disability Studies and the social model of disability was born in direct confrontation with this pathologising and paternalistic framework. The lexicon of the social model involves rejecting the term 'chronic illness', with its overtones of private tragedy, suffering and stigma, in favour of the more neutral descriptive term 'impairment' (Oliver, 2016). By the same token, 'disability' took on its new, politicised meaning as a social relationship of oppression of people with impairments, parallel to sexism and racism.

With this move, the concept of chronic illness was subsumed by the universalising concept of impairment (itself rejected by many groups). At the same time, the discussion of impairment and its effects was, if not suppressed, then certainly sidelined. Oliver (2016) explains that severing the causal link between impairment and disadvantage was crucial to the disability rights agenda because the latter was a demand for society to address disadvantage not through medical treatment but through social and legislative changes. Linking impairment to disadvantage would only weaken the narrative and undermine the case for change.

Early proponents of the social model, therefore, did not seek to deny the reality of pain, weakness and suffering in many disabled people's lives, but sought to draw a clear distinction between 'disability' as a public, social phenomenon which should be addressed through political action, and 'illness' as the domain of the private to be addressed by medicine and allied therapeutic professions. This left the experience of chronic illness outside the arena of politics and political action.

Going even further, disability scholars Swain and French argued that:

"Pain and chronic illness are neither impairments nor restricted to the experiences of disabled people. Non-disabled people experience both pain and chronic illness."

Swain & French (2000: 571-2)

There was clearly a political expediency to the sharp division between impairment and disability and the bracketing out of impairment. As Tom

Shakespeare notes, rejecting a focus on bodily suffering helps overturn the negative cultural assumption that disability is equated with dependency, invalidity and tragedy (Shakespeare, 2014). Side-lining the unavoidable restrictions imposed by impairment in favour of exploring socially-created restrictions to participation strengthens the argument that the disadvantage faced by disabled people is socially produced and must be addressed through social and political action.

However, as Patricia de Wolfe observes, the separation of chronic illness from disability, whilst liberating for some disabled people, has further marginalised others:

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

de Wolfe (2002)

Bringing back impairment

Even early on, voices from within the *Disabled People's Movement*, informed by the feminist standpoint, challenged the private and public distinction between illness and disability (e.g. Morris, 1991). Liz Crow noted that:

“Removal of disability does not necessarily mean the removal of restricted opportunities. For example, limitations to an individual's health and energy levels or their experience of pain may constrain their participation in activities.”

Crow (1996)

She called on the movement to ‘bring back impairment’ into the social model of disability in order to restore a holistic perspective on the lives of disabled people, and she posed the very pertinent question: if we can't articulate the nature of our impairment (especially when the latter is not readily apparent to the observer) how can we formulate our needs and demand that society meet them?

More recent scholarship on disability has recognised the need to incorporate impairment into the social model of disability. Carol Thomas notes that the social model is not a theory of disability in that it “doesn't explain why social barriers come into existence in the lives of people who have types of impairment.” (Thomas, 2012). Tom Shakespeare notes that many disabled people say that impairment is an important part of their experience. A discipline that 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).

However, despite these, and other arguments for a theory of impairment (e.g. Hughes & Paterson, 2006), and an acknowledgement of other impairment-specific movements for social change, chronic illness has, by and large, not been theorised as a form of impairment with its own attendant experience of disability and disablism. There may be some condition-specific research, for example showing that people with hepatitis C face discrimination, disadvantage and exclusion in the process of applying for welfare benefits (Mack & Paylor, 2017). An exception to this is the work of Ana Bê, who advocates: “the need to understand chronic illness as a ‘category of impairment’ from a disability rights perspective” and demonstrates that people living with chronic health conditions “are equally affected by structural, cultural and external circumstances” (Bê, 2016).

Sick or disabled? Anti-austerity activism

Away from academia, the tensions between chronic illness and the *DPM* have been mirrored in activists’ responses to UK welfare reforms since 2010. A new generation of disability activists living with chronic illness (many of whom were involved in the Spartacus Network) emerged in response to attacks on social security for those too ill to work.³ They (this author included) identified themselves as ‘sick’ to highlight the difference in their position in the labour market to that of ‘healthy’ disabled people who defend the provisions and measures to enable their right to work. (See Sue Marsh, Kaliya Franklin, Jane Young for use of the term ‘sick’ in anti-austerity activism.^{4, 5, 6})

The emergence of a ‘sick’ identity was met with some resistance from disability rights advocates in the UK. For Liz Sayce:

“Arguing that you are sick entrenches, rather than disrupts, the negative association of “disability” with incompetence.”

Sayce (2014)

The focus on impairment and the defence of social security was seen as a return to the medical, or ‘tragedy’, model of disability. Mike Oliver wrote that ‘sick’ activism was undermining the cause of disability rights and reversing 30 year of the *DPM*’s progress by reintroducing the ‘victim’ narrative that was so hard to overcome.⁷

So the rejection of the ‘sick’ identity in disability activism, coupled with the rejection of chronic illness as a valid unit of analysis in Disability Studies,

has meant that 'chronic illness' does not have currency in the UK *Disabled People's Movement* and is not accepted as a sub-group of impairment in the way that neurodiversity or learning difficulty is.

Tellingly, beyond patient representative organisations for specific diseases, there are no representative organisations for people with chronic illness in the UK. As activist Kaliya Franklin noted:

*“The shiny pink elephant in the room of policy makers and certain sectors of the disability lobby is the complete exclusion of sick people from this group.”*⁸

When the government consults with disabled people and their organisations on matters of policy or services, there is no one representing people with energy-limiting chronic illness, except for conditions with the highest public profile, such as cancer. In health and social policy discourse, the term 'long term health conditions' or 'long term conditions' is used to differentiate illness or disease from impairment resulting from injury or genetic inheritance (Bê, 2016). But to those of us involved in the virtual community of chronic illness, the meaning of the term is narrower than 'long term health condition'.

5. Conclusion

This discussion paper is intended to stimulate reaction and debate – from the *Disabled People's Movement (DPM)*, the Disability Studies community and beyond – to my framing of 'chronic illness'. The coherence of my concept of chronic illness lies not in medical diagnostic categories but in a shared experience of impairment and disability which is articulated through social media networks using the hashtags #chronicillness and #spoonie.

The core of this impairment experience is significant activity restriction through very limited units of energy which can require extreme rationing, for which I propose the term 'stamina impairment'. With chronic illness, pain, fatigue and malaise are of a different dimension to that experienced by non-disabled people or by 'healthy' disabled people. Therefore, chronic illness is distinct from impairment, rather it involves impairment that affects global function – both physical and cognitive – and is fluctuating and cumulative in nature, rather than localised to a specific limb or organ and stable.

Demographically-speaking, stamina impairment affects a large number of disabled people, especially in the disability benefit caseload, and yet is not recognised or accounted for within the *DPM* or by government policy and administration.

Chronic illness has rarely been explored within a social model of disability. This may be because, with global or systemic impairment, the barrier-removal paradigm at the heart of the original formulations of the social model only has limited success in eliminating disadvantage.

However, it is clear from chronic illness communication on social media that, as well as unavoidable restriction of activity, there are restrictions to our lives, activities and wellbeing that are entirely created by social and political responses to chronic illness. These are forms of oppression, and they have rarely been articulated or addressed by the *DPM* or Disability Studies. Two factors of chronic illness impairment that seem to generate social oppression are discussed in brief: the invisible nature of impairment and the power relationship between lived experience of the body and medical/scientific systems of knowledge of the body and disease.

Using the framework of disability or 'disablism', this emancipatory research project will fully explore the nature of social oppression faced by people with chronic illness and produce an agenda for social change. In doing so, we will interrogate the emancipatory goals of the *DPM*, such as 'full inclusion in society' and 'independent living', as well as other principles, such as

citizenship and the discourse of human rights, to assess which principles best capture the needs and aspirations of people with chronic illness.

The intellectual history of the *DPM* and Disability Studies explains why the term 'chronic illness' was rejected as a unit of analysis. It also explains why political activism by those of us who identified as 'sick' (rather than or as well as 'disabled') was not embraced by the previous generation of disability activists. This discussion paper is an attempt to overcome these divisions without threatening the integrity of the *DPM* or its founding principles.

I believe that the only way for people with chronic illness to have our voices heard and our needs and aspirations accounted for is to adopt a social model of disability. I hope, in turn, that expanding the understanding of disability and disablism to include the experience of people with chronic illness will strengthen and enrich the *DPM* and the discipline of Disability Studies.

It could be that the hypothesis presented here for the coherence of 'chronic illness' as a unit of analysis and action is proved wrong as a result of our forthcoming research. It may be too rooted in my personal experience of living with ME, and have very limited application to other diagnoses. It could be that social and political activism are already too embedded in specific patient communities (HIV, cystic fibrosis, ME, for example) and that the impulse to transcend disease labels and find common cause is too weak.

I am grateful to the DRILL research programme for the opportunity to find out.

Join in and be part of this research process with news, blogs and opportunities to get involved directly in the *Chronic Illness Inclusion Project*.

Sign up [here](#).

Appendix 1. A note on the 'spoonie' metaphor

The chronic illness community is closely related to the spoonie (as well as chronic pain) movement. We conducted an informal poll in August 2017 among our (then) 500 project subscribers to understand how terminology is used. 95% of 153 respondents shared our proposed definition of 'chronic illness' as 'energy limiting illness where fatigue and/or pain and brainfog are a very big part of our day to day experience'; however, only 21% used the term 'spoonie' to refer to themselves. The poll elicited discussion of the term spoonie among those who disliked it for being 'silly' and 'infantilising' as well as connoting a sexual practice.

Wikipedia defines 'spoon theory' as "*a disability metaphor and neologism used to explain the reduced amount of energy available for activities of daily living and productive tasks that may result from disability or chronic illness.*"

The origins of spoon theory

The spoonie movement was born when a college student with lupus called Christine Miserandino was asked by her friend what it feels like to be sick (Miserandino 2003). The friend didn't want a description of the symptoms or medical explanations of lupus. She wanted to try and grasp what it felt like to live day-to-day with a chronic illness. Spoons were chosen at random to become a metaphor for scarce units of energy because the pair happened to be sitting in a café at that moment. 'Spoon theory' is the explanation of how the life of a sick person involves painstaking budgeting of every small action and activity in the day because, unlike healthy people who can take their energy for granted, each small action has consequences for other possible actions, and, if you don't watch out, self-care can be compromised. You need to get to the end of the day with enough spoons to eat dinner and go to bed.

"Sometimes you can borrow against tomorrow's 'spoons', but just think how hard tomorrow will be with less 'spoons'. I also needed to explain that a person who is sick always lives with the looming thought that tomorrow may be the day that a cold comes, or an infection, or any number of things that could be very dangerous. So you do not want to run low on 'spoons', because you never know when you truly will need them."

(Miserandino 2003)

Appendix 2. Statistics on chronic illness and spoonie communication online

There has been no research into the demographic characteristics of the online chronic illness and spoonie communities, e.g. which illnesses and diseases are most commonly associated with the terms. The data presented below derives from commonly accessible social media analysis tools.

It is difficult to measure the volume of social media communication about chronic illness to support my claim that it is a significant virtual social movement. However, the site hashtagify.me ranks hashtags by their all-time popularity with a score of 100 being the most popular at any point in time. #chronicillness has an all-time popularity ranking of 52. For comparison: #LadyGaga 74.2 #Trump 82.1 #disability 60.7 #spoonie 54.5 and #ASD 59.1.

The blog post that launched 'spoon theory' was published in 2003. Since then, the associated Facebook page has 53K 'likes' and over 10K people have adopted the spoon image on their social media profile as a badge of identity (BBC Ouch). There are well over 100 different Facebook groups containing the term spoonie (e.g. Spoonies for Life, Spoonies with Cats, Spoonie Strong, Spoonies UK) providing peer support and social connection.

Twitter hashtag trend analysis also shows how commonly different terms or 'hashtags' are used together in any public post (a 'tweet'). Analysis of the term #chronicillness shows the most highly correlated hashtag was #spoonie at 20.7%, followed by #chronicpain at 20.3% (Figure 5). The term #spoonie was most highly correlated with #chronicpain at 17%, followed by #chronicillness at 12.8% (Figure 6).⁹ [The thickness of line connecting the terms indicates the degree of correlation.]

In terms of medical diagnoses, the most frequency correlated health conditions are chronic pain, fibromyalgia, ME/CFS (and associated terms), and lupus. My own immersion in the chronic illness and spoonie communities suggests that EDS (Ehlers-Danlos Syndrome), CRDP (chronic regional pain syndrome), POTS (postural orthostatic tachycardia syndrome), chronic Lyme Disease, Crohn's disease and Irritable Bowel disorders. To a lesser extent, rheumatoid arthritis, multiple sclerosis, endometriosis are among other conditions which are commonly associated with the chronic illness identity.

Thus, the data on #spoonie and #chronicillness communication supports my assertion the two terms are closely related in meaning and usage, and that pain and fatigue are core features of the chronic illness identity. The hashtag #brainfog is not within the top ten for #spoonie or #chronicillness; however, analysis of the #brainfog hashtag shows high correlation with #spoonie, #fibro, #MEcfs and #chronicillness.

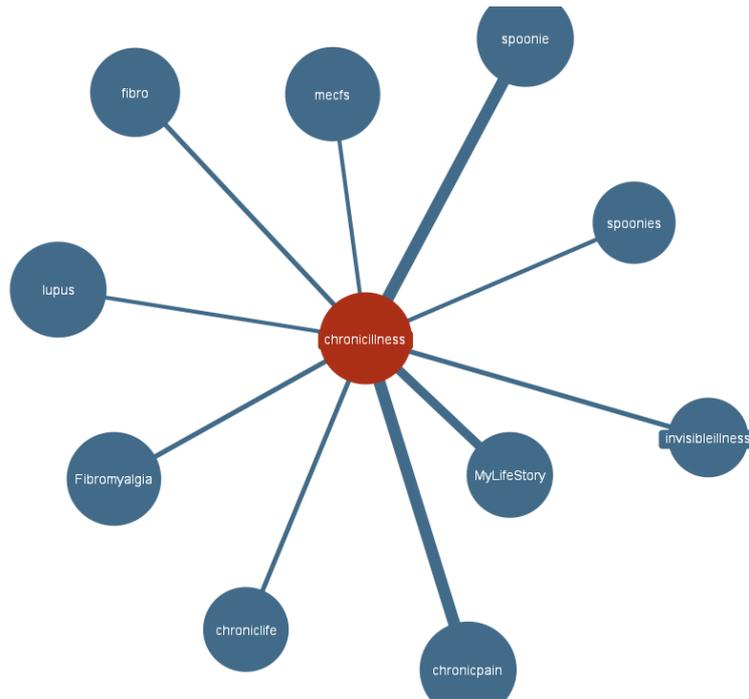


Figure 5. Top 10 Twitter hashtags correlated with #chronicillness on 02.08.17.

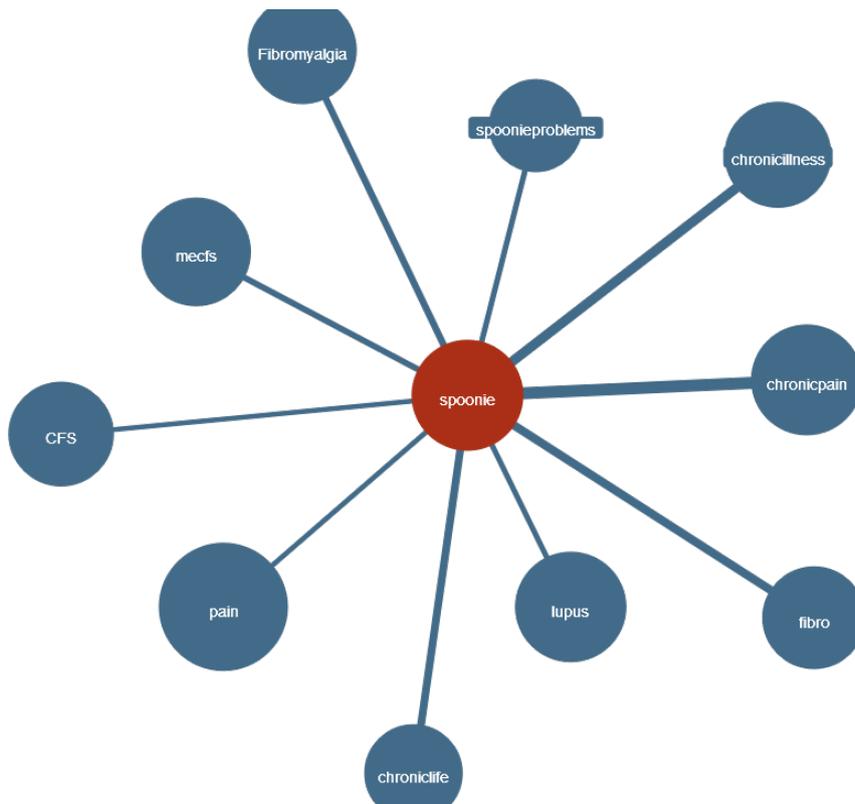


Figure 6. Top 10 Twitter hashtags correlated with #spoonie on 25.07.17.

Endnotes

1. For more information about the DRILL programme of disability research see <https://www.disabilityrightsuk.org/policy-campaigns/drill-programme>
2. Ableism in Academia was held at University College London on 23rd March 2018. See <http://www.ucl.ac.uk/live/ableism-in-academia-2018>
3. See <https://spartacusnetwork.wordpress.com/about/>
4. <https://diaryofabenefitscrounger.blogspot.co.uk/>
5. <http://blogs.independent.co.uk/2012/07/31/benefits-and-targets-sickness-and-disability-are-not-the-same/>
6. <http://disabilityrightsuk.blogspot.co.uk/2012/10/disability-chronic-sickness-and-work.html>
7. See <https://jennymorrisnet.blogspot.co.uk/2013/09/welfare-reform-and-social-model-of.html>
8. <http://blogs.independent.co.uk/2012/07/31/benefits-and-targets-sickness-and-disability-are-not-the-same/>
9. Analysis by hashtagify.me on 3rd August 2017.

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Catherine was previously involved in running a local peer support group for people with M.E. All her work to date has convinced her that people with certain forms of chronic illness are among the most excluded and overlooked groups in society. This is how the *Chronic Illness Inclusion Project* came about.

To find out more about the *Chronic Illness Inclusion Project* visit: www.inclusionproject.org.uk

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