

RESEARCH

'They Can Replace You at Any Time!': (In)Visible Hyper-Ableism, Employment and Sickle Cell Disorders in England

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This paper explores how ableism interacts with multiple identities in the workplace, in order to understand barriers and enablers to employment. Two focus group discussions and forty-seven semi-structured interviews were conducted with people who have sickle cell disorders (SCD). In England, SCD primarily affects people of Black African and Black Caribbean descent and is understood as an invisible disability because its signs and symptoms can be hidden. When exploring how participants give meaning to their experiences, we find that ableism acts as an embodied social sorting that foregrounds disablism, sexism, and racism, requiring research participants not only to be 'fit for' work but also to 'fit in' at work. This makes invisible disabilities visible, allowing implicit and explicit disability discriminations. We advance theorizing in this area, by offering more nuanced conceptions of ableism within the workplace. Ableism is linked to discriminatory practices and power-dynamics which prevent access to employment, retention and career development and also challenge ensuring health for any encumbered body.

Keywords: ableism; intersectionality; employment; ethnicity; sickle cell

Introduction

This empirical research study took place in England in 2018–2020 before the pandemic occurred. It involved understanding employment barriers and enablers for people who have an inherited genetic condition called sickle cell disorder (SCD). While SCD affects men and women of African, African-Caribbean, Middle-Eastern, Indian and Southern European descent globally, in England it occurs mainly in British people of African and African-Caribbean origin. It is one of the main inherited genetic conditions affecting around five percent of the global population and is the most common genetic condition in the United Kingdom (UK), affecting around 15,000 people (Dyson 2019).

In some people, SCD can be a mild episodic or chronic condition, while in others it can lead to disablement and/or is acute and life-threatening. For individuals, there is no certainty about how the condition will develop and consequently, there is no typical case of SCD for employers. SCD may also be understood as an invisible disability because the signs and symptoms, such as fatigue and chronic pain, can remain hidden. Symptoms can be exacerbated by extremes in temperature, dehydration, and stress. Yet, most of our research participants would be considered to have an invisible disability and thus we expected that more visible aspects of identity associated with workplace discrimination such as ethnicity or gender would have more salience.

However, it was ableist norms in employment that were foregrounded in interviews, even though participants communicated this without specifically mentioning the term 'ableism' itself. Hence, our paper takes an intersectional approach to the analysis of the prominence of ableism within and the impact of this on, the experiences of workers with SCD. Grounded in Critical Race Theory (CRT) and Black feminism, the term intersectionality was devised by Crenshaw (1989), who argued that to understand Black women's multiple experiences of discrimination in employment, an analysis of the ways in which gender and race intersect was needed. Single axis analysis alone tended to obscure power dynamics, and, for Crenshaw (1989, 1991), the role of intersectional analysis, was to provide a tool that revealed discriminations happening along multiple axes of analysis. Yet, it was not identity work *per se* that was important, but rather what power relationships were revealed through identity struggles in order to politically combat discriminations.

We focus on how ableism intersects with invisible disability, visible disability, gender, and ethnicity, thus taking an explicitly intersectional approach. In so doing, we address two key questions: 1) what impact do ableist norms

have on experiences of workers with an invisible disability; and 2) how does ableism inform and interact with other discriminations, when making sense of their experience? The paper begins by presenting extant understandings of ableism and its salience within work and employment. Research methods are then detailed, emphasising its participatory nature, so as to avoid ableist assumptions and outcomes. Findings are then presented and structured around the two research questions. In the discussion, the utility of our intersectional approach is highlighted in demonstrating how ableism is foundational to both sexism and racism experienced by participants, and the way in which ableism (Campbell 2020) is entrenched in practices of social sorting, creating a perpetual loop of encumbrance for these workers.

Understanding Ableism in the Context of Employment

Ableism marks a theoretical shift away from a social model of disability. The social model was formed in opposition to a medical model, that viewed disability as biological pathology to be cured, fixed, or rehabilitated. Instead, the social model makes a distinction between having a physical, cognitive, or sensory form of impairment and the experience of becoming a 'disabled' person by encountering negative assumptions, discrimination, or barriers in society (Oliver 1983, 2013). The focus, as a social constructionist approach, is emancipatory in advocating politically for structural change to accommodate the rights of disabled people.

Ableism, by contrast, is more interested in the refusal to accommodate any 'body' that does not fit structural norms, such as in this case, of employment. While disablism seems to focus on 'differences', ableism is about embodied 'sameness' (Goodley 2014). Campbell's (2008, 2009) theory of ableism and its features, such as microaggression, and in particular the idea of internalised ableism, were inspired by the idea of internalised racism found in CRT. According to Campbell (2020: 204–205), ableism is typified by:

... a system of causal relations about the order of life that produces processes and systems of entitlement and exclusion. This causality fosters conditions of microaggression, internalized ableism and, in their jostling, notions of (un)encumbrance. A system of dividing practices, ableism institutes the reification and classification of populations. Ableist systems involve the differentiation, ranking, negation, notification and prioritization of sentient life.

While disablism is disability discrimination specifically against persons with disabilities and their interests, ableism implicitly or explicitly discriminates in favour of able-bodied people. Difference is conceptualised in terms of what bodies 'fit' or do not 'fit' productive capitalist employment. It is the visible body that is set up as a 'site of difference' and where 'othering' occurs, and identity is understood as embodied (Brown & Leigh 2020). The process of othering is primary, as ableism is formed with respect to bodies that are different and do not 'fit'. This suggests that the juxtaposition between disability and ability as co-constitutive (Goodley 2014) is not clear cut, as ableism intersects with other dimensions of social and cultural oppression.

A focus on discrimination or on adjustments in employment, can restrict analysis to visible barriers facing workers with disabilities in the workplace, without examining the structural norms that make up the workplace itself. Structural norms might include ableist assumptions, about, for example: time (e.g., length of the working day, shift work, speed at which tasks can be accomplished, number and timings of breaks); ergonomics (e.g., concerning equipment, workstation organisation, and physical distance); and the physical environment (such as temperature). There are differences within types of roles (and employment), as some settings make it more difficult to resist ableist assumptions, for example, zero-hour contracts, hourly payments, and overtime.

Campbell (2020) thus elucidates there is a presupposition of assimilation in policies of reasonable adjustments. Yet, she notes how the norms of processes of assimilation, considering use of technologies in work and managerial practices, constantly changes (Campbell 2020). In turn, such ever-changing ableist norms cause harm in the workplace through creation of differences between groups, ensuring privileges for some over others around embodied 'otherness' (Acker 2006; Campbell 2020; Foster & Wass 2013). Hence, ableism becomes pertinent to investigate as a site of discrimination, as we know little about if and how it informs or interacts with other discriminations.

The effects of ableism on employment experiences and research

In order to understand the barriers disabled workers face in employment, studies have increasingly focused on ableism in: access to work (Jammaers et al. 2019; Jammaers & Zanoni 2021; Kwon 2020; Mellifont et al. 2019); management structures and spaces (Kulkarni & Lengnick-Hall 2014; Van Laer et al. 2020); and treatment of disabled workers as 'other' (Jammaers et al. 2016; Mik-Meyer 2016; Williams & Marvin 2012). The concept of ableism has been developed in terms of identity regulation (Jammaers et al. 2019), resistance to ableism by highlighting ableist norms (Kwon 2019) and the needs of social capital (Jammaers & Zanoni 2021) but often without a serious engagement with ableism theory itself (Campbell 2009, 2020). Empirical studies from within the field of organisation studies have disregarded disabled people's norms of research (Oliver 1983), in that they tend not to be participatory, co-produced, rights-based, applied, or emancipatory, suggesting therefore that ableism functions as a purely theoretical category. To this extent, even research itself on ableism can be considered ableist and has been questioned by researchers who themselves have visible and invisible forms of disability (Brown & Leigh 2020; Mellifont et al. 2019).

Empirical studies examining ableism have mostly focused on doing research *on* or *about* people with visible disabilities (Baldrige & Kulkarni 2017), people who identify as having a disability (Jammaers & Zanoni 2020; Van Laer et al. 2020) or have tried to revalorize the disability identity in terms of abilities (Jammers et al. 2016). Investigations have included the functional implications of impairments (Randle & Hardy 2017) as embodied career boundary, for example, in determining the feasibility of certain careers and in limiting opportunities, for instance, with regards to promotion (Williams & Mavin 2015). Yet, in the above, disability is always assumed as a binary category to the 'able body' rather than viewed as contested identity or along a fluctuating continuum of impairment with more or less need for adjustments: particularly relevant and applicable to people with SCD.

Workers with invisible disabilities can also look 'fine' or 'able' but can still experience ableism in microaggressions, internalised ableism, and policing of their bodies and work practices (Kattari et al. 2018). The very nature of having an invisible disability or chronic illness in a workplace setting requires labour, of staying well and keeping a condition hidden, but this can be stressful (Dyson et al. 2021). Furthermore, the required emotional labour itself can render the disability visible and can necessitate disclosure to the employer (Finesilver et al. 2020).

Ableism, therefore, has significant potential effects for workers with invisible disabilities. As such workers can pass as 'able' and sharing medical information is discussed with anxiety, in terms of disclosure, as it could change the way they are viewed and treated (Kattari, et al. 2018; Norstedt 2019; Santuzzi et al. 2014). They are also expected to personally engage in the education of their employers about their conditions and the necessary reasonable adjustments required (Brown & Leigh 2020; Kattari et al. 2018). Many workers with invisible disabilities or chronic conditions, whether physical or mental, congenital, acquired, or episodic, will not have a choice about disclosure (Finesilver et al. 2020). This is because skilled manual labour jobs are more likely to rely on physical presence (rather than remote working), or require vision (driving/operating mechanical equipment), or dexterous hands (sorting, packing, processing raw food, or other production-line activities), or are situated outdoors (agricultural labour; building work). In other words, occupational class intersects with ableism and the literature shows an additional gap in this respect.

Key themes emerging from this extant literature are addressed within our analysis. First, with respect to the application and further development of ableism theory as elucidated by Campbell (2009, 2020), we explore its applicability and relevance to workers with invisible disabilities. In the specific case of our research participants, we focus on the way that ableism was foregrounded in their recollections, which includes the many different forms it can take. Secondly, applying an intersectional focus reveals power dynamics in employment, allowing us to see how ableism informs and interacts with other discriminations.

Research Methods

Ethics

This study took place from 2017 to 2020 and obtained all necessary university ethical approvals. The project worked with people with SCD and two of their voluntary organisations, the Sickle Cell Society and OSCAR Sandwell, as partners. It used a method of 'democratic co-production', meaning that research is co-produced with people with SCD and their organisations, such that people could contribute to the research process as and when it suited them. This ensured research involvement does not become an obligation for the whole duration of a project (Ryan 2012). This is especially important as the symptoms of SCD can be unpredictable and variable from one individual to another. We were especially conscious of 'energy impairment' (Hale 2019) as some people with SCD will have fluctuating levels of energy or serious fatigue.

Data collection

Before any focus group discussions or individual interviews, we disseminated our participants' information sheets, gave people the opportunity to ask questions, and ensured written informed consent was given (Silverman 2020). We developed an interview topic guide based on a literature review (Berghe & Dyson 2020) but wanted a critique and check of those priorities. People with SCD led two focus group discussions (Barbour 2008) to formulate questions and to share their understandings of what had been the normative barriers and enablers to their employment. For example, it was noted that an important question to ask was if work had made people ill or contributed to disability? Forty-seven interviews were conducted with people with SCD, incorporating the feedback from those focus group discussions.

Participants

We were cognisant of the need for a method that could explore the interaction of different diversity dimensions and sampling was purposive (Bryman 2016). We were able to ensure a range of ages (18 to 66) with an average (mean) age of forty-one years old, representation of binary genders (25 female, 22 male), ethnicities (Black African, Caribbean, and Indian descent as well as 'other' ethnic groups), and differing variations of the condition across the life-course. Interviews were based in London (24) and major cities in the Midlands (15) and the north of England (7). Addressing issues around occupational classification emerged as important from the literature review and the sample included a range of occupations (e.g., lawyer, biomedical scientist, mechanic, factory worker, and shop assistant); those who were self-employed (e.g., entrepreneur, actor, model, and trader); and those who were currently unemployed.

Data analysis

All interviews were digitally recorded, transcribed, coded, and analysed using the qualitative software programme NVivo 12 (Bryman 2016; Silverman 2020). Interview data was analysed initially according to the themes identified in response to the interview questions and by prioritising understanding of what enables employment or acts as a barrier. People with SCD do not always consider themselves to have a 'disability' and explained that other features of their identity were more important to consider, which meant considering intersectionality as tool to aid analysis (Crenshaw 1991). 'Ableism' as a term was never explicitly referred to by participants. Nonetheless, many of the experiences they recounted could be usefully considered as falling within that conceptual category. Exploring this, explains the purpose of our analysis (Layder 1998). Sticking close to Campbell's (2009, 2020) theory, we began by coding for words like: 'able', 'able-bodied', 'normal', 'healthy', and 'fit' to understand 'how ablebodiedness circulates' and became linked to invisible disability in terms of 'ablement' as dividing practice at work. Within that coding, we then looked for examples of the main features of ableism: 1) microaggressions; 2) internalised ableism; and 3) encumbrance (Campbell 2020). While these features of ableism were developed using CRT (Campbell 2008), we explored if 'race' was truly foregrounded. Using intersectionality as tool to understand layers of discrimination (Crenshaw 1991), we then examined concepts of 'differentiation, ranking, negation, notification and prioritisation' within disability and then examined 'dividing practices' (Campbell 2020) of sexism and racism.

Limitations

There were some limitations to our study. While we tried to be inclusive in our sampling framework, we did not interview any lesbian, gay, bisexual, intersex, transgender, and queer or questioning (LGBTIQ+) people. In fact, the one person who was identified through snowballing (Bryman 2016) as not heterosexual declined an interview. This possibly represents another form of 'ableism' and the silencing and/or guarding of experiences and identities that do not 'fit' heterosexual norms – whether Black or white – in the workplace, but we are not able to make any further analysis of this.

Findings

Our empirical findings are structured around the two research questions: 1) what impact do ableist norms have on experiences of workers with an invisible disability; and 2) how does ableism inform and interact with other discriminations?

Ableism, social sorting, and making the invisible visible

We found ableism, as experienced in workplace settings by our participants, was consistent with Campbell's (2020) idea of *socially sorting* visibly embodied markers of identity pertinent to disability, gender and ethnicity. We present specific examples of each of the different elements of social sorting, namely 'negation', 'notification', 'ranking', 'differentiation', and 'prioritisation' of the able-body (Campbell 2020: 204–205). This embodied social sorting affected access to, as well as retention and progression, when in employment. By not allowing a disability to remain invisible, participants were required to negotiate, a range of different discriminatory practices, when making sense of their experience.

a) Negation

While there is no such thing as a fully physical, cognitive, or sensory 'able-bodied' employee, this norm nonetheless pervaded employment, including time management practices, use of technologies, and formal work policies. That was if participants could gain access to employment, as many company recruitment policies could make it difficult to be shortlisted and satisfy probation criteria. To illustrate, Fanaka (Male, Black African, 20s, North) gave the interviewer a written example of a job specification. It was so carefully worded, that it led Fanaka to rule himself out from applying for the job:

It's got three columns; quality, reason for requirement and to what level. So, quality; muscular-skeletal injuries or problems exacerbated by lifting. The reason for the requirement; lifting boxes containing computers and equipment and long periods of working at desk. And to what level; able to lift up to 16 kilograms for women, and 25 kilograms for men, and be able to be desk based with regular, reasonable breaks. That's the first one. Number two, eyesight. Reason; long spells of computer work. Level; does not worsen with reasonable adjustments. Quality; back, arm, wrist or hand issues, nature of work carried out means long periods spent at desk using keyboard, mouse and laptop. To level; does not worsen with reasonable adjustments. Hearing difficulties, telephone work required by role does not worsen with reasonable adjustments. The name of the company promotes equal opportunity and will make any necessary reasonable adjustments to ensure the post-holder can fulfil the role. OK. So, they're saying they'll make adjustments but they've already ruled out certain... [Interviewer reading aloud the written job description provided to Fanaka by a prospective employer]

The job description appears to anticipate that some applicants might apply who would need reasonable adjustments in terms of ergonomics, prolonged sitting, and/or use of technology. Yet, it pre-empts such applications by workers with

disabilities and phrases the job requirements around the idea of being 'able' and any impairments 'not worsening' thus actually thwarting the intentions of the 2010 Equality Act.

In this example, reasonable adjustments are arguably reduced to an empty performance by a discriminatory job specification which is grounded in ableism. No explicit, legally challengeable, disability discrimination has taken place, but in embedding ableist assumptions into a job description, certain bodies have been intimidated and *negated* out of even applying for the job in the first instance. This would exclude pregnant women and people with visible disabilities and/or those that have disabilities that can become visible.

b) Notification

When we asked participants if Human Resources (HR), Occupation Health (OH), or the line-manager could enforce reasonable adjustments in the workplace, we heard that this was only possible to a certain degree. When Nwuso (Male, Black African, 50s, London) explained the case of a male friend with SCD he had been involved in supporting, it was clear that HR and OH were also working with an able-bodied norm of what constitutes illness in coming up with adjustments – namely that it is acute, rare, time-limited, recoverable, and with the employee responsible for a quick recovery. Ableist norms of illness affect how procedures are quantified in absence management policy and systems of checking worker productivity. Nwuso related:

Almost every year he'd been referred to occupational health and occupational health's report had been pretty standard; it falls within the Equalities Act, need to make reasonable adjustments. He was given parking space so he could drive into work but they felt that was the only reasonable adjustment they needed to make. So, they started him off on a sickness procedure which apparently is what happens when somebody who's got a medical issue, you know, when they sort of get tired of that person. In effect you get rid of that person.

Participants related the ways that technologies such as absence monitoring, targets and productivity measures are used as tools to enforce ableism in differentiation and ranking of bodies and in this case, *notification* if productivity targets were not being adhered to because of absences. A condition such as SCD that entails pain, loss of energy and unavoidable sickness absences therefore becomes problematic and highly visible.

c) Ranking

Similarly, participants, working in differing industries, explained that norms of so-called 'flexibility' linked to technology were not concerned with inclusion but more about soft-skills, presenteeism and being able to pick up additional work if someone fell ill, especially if a practical or administrative task needed doing. This was a way in which employees could be *ranked* according to how present or flexible they were. However, technology was rarely used to make reasonable adjustments for the employee or else it was only partially or tokenistically implemented.

For instance, Kamil (Female, Black African, 20s, London) was given assistive software in employment and while she made requests for a laptop to able to work from home, and her employer said they would accommodate those requests, this never materialised. Pre-COVID-19 we found many participants struggled to work from home (especially if they were women) and/or gain access to all the technology that would enable this. This meant that despite reasonable adjustments, they were usually ranked as less present, flexible, and able to cover for another's work if someone fell ill.

Fabia (Female, Other Ethnic Group, 40s, London) explained this but in stronger terms:

I know they wouldn't give support because the staff are treated as very disposable so if you're not fit for the work, don't work here.

Fabia makes a distinction between several different meanings given to 'fit' as in: physically able-bodied as in fit-and-healthy; and fittingness (fits or is well-adapted to the environment). Fabia also understood this in the way she tried to create a 'good atmosphere' with her colleagues, so she could take breaks when she needed at work without anyone complaining.

d) Differentiation

While negative differentiation was often used against employees in the workplace, participants also explained that positive differentiation was a way to resist what we analysed as ableism. What makes up the 'normal' of organisational practices also extends to relationships between colleagues, bureaucracy, management, and the general cultural ethos of companies. Idowu (Male, Black African, 30s, London) stated that it was important to gain the trust of the manager by illustrating how hardworking you were through impression management, for example, by picking up other employees' shifts or work when needed. As he said, if there are no contract hours and the manager has to fire someone, he will think 'First in, first out. No, I am not going to, Idowu is a good guy.' In explaining his strategies in resisting what we identify as ableism, Idowu illustrates how work is about more than 'working hard' or doing a job well but also undertaking the performative work and emotional labour of being present, as well as 'fitting in' and getting along with your colleagues

and manager. Yet, this strategy of positive differentiation was not possible for many employees, as the chronic fatigue associated with SCD made it impossible to 'fit' in all this extra emotional and performative labour.

Often participants related becoming small-scale survival entrepreneurs (e.g., actor, model, t-shirt printing; business card printing; hip-hop musician; illegal trading) or thinking about starting their own business and taking financial risks (without any training) because their SCD was not compatible with current working norms. In addition, what might previously be a strong distinction between public work and private pastimes has, because of economic pressures, led to a situation where many have to try to monetize their private activities. We found boundaries between private home life and public working life were collapsing for the participants.

e) Prioritisation

Pre-COVID-19, the divisions between work and home life were already becoming blurred, with work extending into the home in evenings and on weekends. Social media, computers, and telephones meant that people had to be 'available' and 'switched on' all the time – even when they were ill. For example, sickness policy often required an employee with SCD to phone in to their manager or HR. This was very difficult if someone was in hospital or in midst of a pain crisis. Carl (Male, Black Other, 30s, Midlands) gives an example of such pressures for a self-employed person:

I would be on the other end of the phone, unbeknownst to them I'm high on morphine, I'm in so much pain, but I'd put on my best telephone voice and go, 'Hi, let me just look in the diary and see if I'm available on that day.' I'd be shuffling through the paper making sounds and I would be like, 'Oh I'm really sorry, no, on that day I'm working elsewhere.' Really, I wasn't working nowhere, I just knew that I'm not going to be ready for that day. So, I...it was really bad.

Carl also illustrates the ways in which technology allows the person with SCD to pass as able-bodied and keep his SCD invisible. In the above example, the able-body is prioritised at all times, even in the virtual environment. Yet, overall, the social sorting described above in all its aspects was about keeping certain bodies out of the workplace.

Ableism in interaction with other discriminations

This next section digs deeper into the experiences of the participants to highlight the ways that ableism interacts and informs with other discriminations, and where we found that ableism was foregrounded. Participants experienced: a) internalised ableism; b) microaggressions; c) demands of (un) encumbrance (Campbell 2020: 204–205); and that this led to d) implicit and explicit disability discriminations as well as e) hyper-ableism.

a) Internalised ableism

In comparison to those with visible disabilities, most participants spoke about passing as 'normal', 'able', 'capable', 'reliable', 'healthy', or trying to 'fit' their workplace setting, thereby internalising ableism (Campbell 2008) as the 'norm' of condition of employment. For instance, Sefa (Male, Black African, 40s, North of England) explains, 'I was treated like I was a normal worker. My employment experience was quite positive in that sense.' He also states that he had not experienced racism but in stating this, the expectation of non-racist treatment becomes correlated to fitting in with ableist norms. In the interviews, fears of comparison with the 'able' or 'normal' were often reported in industries such as services, retail or manufacturing; sectors where insecure contracts, low pay, and flexible working conditions meant that workers could be more easily penalised and lose their jobs if they or their SCD became too visible. As a participant related: 'I did complain but there is no one to listen. They say that you work or you don't work' (Focus Group Two).

b) Microaggressions

Participants in all sectors described everyday micro-aggressions in the workplace. This often involved others questioning their rights to reasonable adjustments; a micro-aggression we analysed as based on an ableist disbelief of an invisible condition, but possibly also a racist disbelief of any entitlement to reasonable adjustments. For example, Grace (Female, Black Caribbean, 30s, London) explained:

I did get allocated a disabled space so I did have a problem with the receptionist when one day when she saw me parked (...) she came out to tell me that I am not allowed to park in that space. And I said, 'I have got a blue badge.' And then she said to me, 'Well does it belong to you?' So even little stuff like that.

Co-workers and senior management set the tone for – and controlled – the office culture. They were responsible for micro-aggressions that revealed, for example, how gender and racism were also part of ableist workplace norms. Several women reported that they had experienced casual sexism and sexual harassment in the workplace, often focusing on their appearance and sexuality. This particular example from a female participant illustrates how micro-aggressions also became simultaneously sexist, racist, and grounded in ableist assumptions:

Those people that you sit with day in and day out that they go for the fag breaks, they go for the pub crawls and you are not there with them. They are the ones that come back and say, 'Oh, he was not at work the other day,

what was wrong?' This is the gossiping culture as well. I don't want to use that word, but I find that the school ground attitude doesn't change, it goes into the workforce whereby people create problems for others. And I have found with this condition, it's the racial aspect as well because they tend to think that Black people are lazy in a way when we get certain jobs because they give you excuses, 'Oh he was okay, on Tuesday? Why isn't he here on Wednesday.' So, it's a lot of aspects (Focus Group Two).

Her colleagues look at her physical appearance and perhaps not being able to see how ill she is, judge her as 'able'. Hence, she is not deserving of reasonable adjustments and this quickly becomes racist: if Black people are reduced to only their bodies (Shilling 2012) and if that body seems 'able', they must by (racist) extension be lazy. In this way, the penalties of ableism at work were greater for Black people and more dangerous in overt experiences of racism that several participants related.

However, there were situations where 'race' did not seem to matter and invisible disability or other features of identity had more salience, such as in participation in after-work drinks. We posit that this could be correlated to an 'ethno-cultural ableism', where who is 'able' is defined in terms of a racialized neoliberalism. This ensures – within the diffusion of working practices and technology – that who belongs 'properly' (Skeggs 2014) is a nominally implicitly part of the dominant ethnicity, its bodily norms, dispositions, and explicitly in its social and cultural practices. It was this idea, alongside being 'unencumbered', that was key to understanding ableism.

c) Demands of (un)encumbrance

Despite the embodied costs to a worker, the combination of austerity, racism, and a hostile benefits system meant participants were often 'grateful' to have jobs and to guarantee they were viewed individually as 'good' workers and part of a collective, contributing to society. Invisibility became critical to the idea of ensuring that they were not a hindrance or encumbrance at work. In order not to be seen as getting adjustments they did not deserve, they had to illustrate 'un-encumbrance' (Campbell 2020). Participants recounted that they were fearful of sharing that they had a condition, having co-workers find out or even showing they had a disability, particularly as ableism could lead to implicit and explicit discrimination.

I could never dare walk into a meeting or into a work place with my walking stick that was like, that would ruin my career (...) So, I had to kind of teach myself to walk again and bear the pain and suffer it the next day or week or whenever that pain would increase. So, it was me creating an illusion of great health and me trying to maintain that (Focus Group One).

The idea of non-encumbrance as an ableist norm in the workplace caused psychological and physical harm (Campbell 2020). For example, a participant explained how a new manager was not attentive to reasonable adjustments needed by his condition and did not understand how a cold environment could make a person with SCD ill:

So sometimes they will send me to go and do stuff in the freezer, which is cold, without providing the proper safety garments (...) We had gloves but body wise it was cold in there, in a cold freezer, and getting food out and stuff like that. So, I ended up having a crisis as usual and would take time off from work (Focus Group Two).

A secondary issue was an inability to ensure inclusive practices and support. This interacted with age, class, gender, and ethnicity, as many of our participants were not in positions of privilege or at stages of career that allowed them, for example, to choose to stay home if they were ill or work flexibly if needed, thus worsening their physical and mental health.

d) Implicit and explicit disability discriminations

As well as making people ill, the demands of an unencumbered body affected the way in which there was a gradual erosion of rights to reasonable adjustments at work. Ora (Female, Black Caribbean, 20s, Midlands) noted how, in her current public sector organisation she had to take her annual leave to go to her hospital appointments or cover when she is ill. When a worker did disclose not being 'fit', often because visibility of disability or illness left them no choice, they again faced the above-mentioned internal social sorting of experiences of 'ranking and differentiation' (Campbell 2020: 204–205), which became correlated to implicit and explicit forms of disability and other discriminations. Bijal (Female, British Asian, 30s, Midlands) gave two examples of how common responses to disability included spatial exclusion and ranking.

I am dyslexic and that went to the head office, and it was a bit of an issue. So, instead of me being, say a C grade, they put me down to a B grade and only doing clinic work and not seeing parents. They did provide me with some gadgets for dyslexia like a computer and stuff like that but that was towards the end.

Bijal's dyslexia is viewed as 'problem' sufficient to warrant demotion, even though this amounted to disability discrimination. She is then excluded from interactions with people and only given reasonable adjustments in a

tokenistic technical way near to the time she leaves her position. She noted how a long period of illness meant that she was absent from work:

I went back again, but no. He said, 'Oh, because it's been quite stressful! I will move you down to another room, it's less stressful.' And then the next thing I know he is advertising my job and I am like, 'Well that's my job?' And he goes, 'Well what made you think you were doing that job?' And I said, 'Because I have been doing it for so long.' And he goes, 'Well not in my book, you weren't doing that job.'

e) Hyper-ableism

The way that SCD interacted with other identities was also salient. Fabia explains how being able to 'fit' with the able-bodied norms became difficult during pregnancy:

When I was pregnant obviously it was not something I could hide, so even to go to your appointments for antenatal, the managers were not happy about it. And then I was working full-time (...) This is a legal right; everybody knows maternity rights. When a woman is pregnant, she can have a rest, she can have a bench if she needs to sit, she can go for her appointments, and they were giving me a hard time when I was pregnant. So, why they would respect somebody who's got a condition if they can take somebody who hasn't got a condition. Somebody who is younger, somebody who maybe is a male?

Fabia realised that the underlying company policy was based around the ableist idea of a young, fit, and healthy single man (Acker 2006). We also note that ableism is foregrounded in her account, and then opens up other explicit forms of discrimination because they too are grounded in the body, such as disability discrimination, sexism, and ageism. Ableist discrimination was clearly becoming part of the contemporary experiences of women with invisible disabilities in employment, with two participants recounting after their interview and 'off the record' that they had both been 'let go' from their employment because they had become pregnant. Furthermore, Precious (Female, 40s, Black Caribbean, Midlands) while working illegally, noted how she was made redundant, allegedly for 'health and safety' reasons, when employers discovered she was pregnant. Pregnancy was being used to exclude women from the workplace, in an extreme form of ableism or hyper-ableism that foregrounds not only a non-disabled but also an unencumbered body.

In the above, workplace relationships reflect an inability to plan for absences and integrate diversity in the workplace. This represents another example of social sorting, which had a knock-on effect and hindered progression and retention, as employees found themselves constructed as problematic. This social sorting affected more visible forms of disability, chronic illness and pregnant bodies, making it seem that such processes were not racialised. However, we found that ableism intersects and informs ethnicity, (visible and invisible) disability, and gender, meaning that certain participants were viewed instrumentally, as not only insufficiently committed to employment and not capable (in embodiment or skills) but also as lacking entitlement to that employment, for example, due to racism (lack of whiteness) or other features of their identity (non-male or unhealthy).

Discussion

Intersectional studies on employment have not addressed multiple discriminations within a group, such as those correlated to invisible disability, disability, ethnicity, and gender (McBride et al. 2015). Ableism explains such discriminations, to understand how to ensure access to employment, retention, and reasonable adjustments in the workplace. In order to protect worker's rights, an examination of what kind of 'human being' polices are being made in function of, in organisational structures, human resources, and management practices, is key (Jammaers & Zanoni 2020; Van Laer et al. 2020). An intersectional analysis (Crenshaw 1989, 1991) was thus useful to understand the workings of ableism (Campbell 2009, 2020) and how it became expressed through people's experiences of the workplace. We find that it acts as an embodied social sorting (through processes such as differentiation), foregrounding disablism, sexism, and racism in employment, explaining how workers had to be 'fit' for work but also 'fit in' at work. Thus, within employment settings, different from the context of other studies on ableism cited in the overview of the literature, we find that 'hyper-ableist' practices also begin to prioritise other embodied norms supposedly necessary to neoliberal workplace functioning.

With ableism so entrenched, and linked to visible embodied differences, we explored the impact it had on invisible disabilities and noted how internalised ableism had become, even among those living with SCD like Carl or Sefa. It was the invisible but accepted norm, which then came back to confront participants in the microaggressions directed against them and explained why disclosure was so difficult, as found in other studies on ableism (Brown & Leigh 2020; Kattari et al. 2018). However, we argue that ableism is foundational to both sexism and racism experienced by our participants, as we saw such microaggressions became sexist and racist when linked to embodiment. Ableism is also entrenched in practices that created encumbrances and disablement and thus again, socially sorting the non-abled out of employment in a self-perpetuating loop as we illustrate in **Figure 1**.

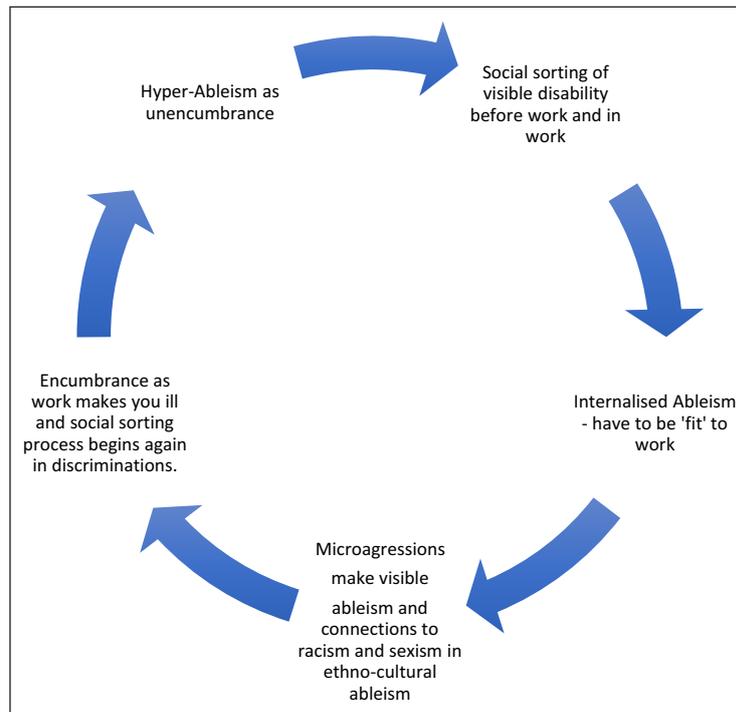


Figure 1: Hyper-Ableism at Work.

Ableism grounds the social model of disability (Oliver 1983) and explains how having an impairment can prevent a person from gaining work; it generates discrimination and disadvantage, if in employment. Working practices can also alter the initial impairment, generating further potential for disability. Ableism, by highlighting the intersectionality of embodiment, goes beyond the social model in explaining oppressions. In the past, employers assumed that the stand-alone independent body necessary for interchangeable capitalist work was necessarily a male body. Now it is clear that it is not the male body that is necessary (Acker 2006) but an unencumbered body.

An intersectional analysis of ableism points to a broader problematic in how workplaces do not conceptualise experiences of physical and mental embodiment across the life-course, such as in maternity or aging. As illustrated by research participants Grace and Fabia, what makes up the 'normal' of organisational practices does not just consist of structural norms but also extends to social and cultural practices, such as in relationships between colleagues, bureaucracy, management and the general cultural ethos of companies. This is because fellow workers can be used to unconsciously reinforce ableist assumptions even if reasonable adjustments are made (Mik-Meyer 2016). The creation of 'unreliable' workers, who place additional pressures on their co-workers, allows interventions, on the basis of being 'fair' on those one works with. This power dynamic creates divisions and resentments among workers and could equally apply to part-time workers, workers with family commitments, and so on. We noted that people with SCD had to use strategies to be viewed as a 'collegial' and 'good' employee in order to deal with possible repercussions of their condition. They have to engage in extra physical and emotional labour to cover how they are not always 'fit' for work (Finesilver et al. 2020; Kattari et al. 2018), but this becomes even more encompassing when you may not always 'fit in' at work and are trying to protect from other forms of discrimination too.

An intersectional analysis also revealed the limitations of such strategies and even policies of inclusion, as we noted that working cultures are often embedded with an invisible ethno-cultural ableism that affected how people can 'fit in', which we outline in **Table 1**.

Table 1: Understanding Ethno-Cultural Ableism.

Model at Work	Typology (Meaning)
Hyper-Ableism	Unencumbered (body)
Ableism	Either explicitly or implicitly deeming an able body to be a necessary requirement of the workplace
Ethnocentrism	Using one's own culture to evaluate other cultures at work.
Ethno-cultural ableism	Expecting others as 'good colleague' to partake in English social and cultural practices linked to work such as going to the pub which have an ableist dimension.

Even if reasonable adjustments were practically (and not partially) given, because they were inherently ableist, participants felt as if those processes had the potential to discriminate against them because they were nonetheless visibly identified as 'other' to the norm (Campbell 2009, 2020). Yet, while ableism works through the idea of unencumbered embodiment, we found that being encumbered was the embodied norm which is applicable to everyone. For example: commitments to hospital appointments and preventative health measures to stay well; needing adjustments for visible disability; having various forms of intergenerational caring responsibilities (both genders); embodied care responsibilities (in pregnancy or aging); and links, requiring outwards-focussed commitments, to other communities, territories, and ethnicities.

Conclusion

Using the example of workers living with SCD, we have suggested that disability discrimination does not fully capture the challenges presented to such people. This is because the contemporary workplace is based around implicit ableist structural norms and assumptions: around bodies assumed to be energised and able to work for extended hours without rest or recuperation; able to withstand adverse workplace environments; able to engage seamlessly with workplace technologies; able to effortlessly undertake emotional labour and performativity; able to negotiate negative ergonomics; and to embody a non-relational ideal independent worker (with no illnesses, no leaking bodies – for example to go to the toilet or breastfeed – or no breaks that their body needs for nourishment), who has no ostensible need to give care through their body or receive mutual support from kin or community.

Through greater understandings of the way that ableism foregrounds other discriminations, we hope that employment policies and practices can begin to address ableist norms to foster diversity and inclusion. Otherwise, with the decline of union power and the main redress as an individual through an employment tribunal, with all the stresses and expenses that that entails, a more likely outcome is displacement from the workplace altogether of minorities who are chronically ill and a foreshadowing of the hyper-ableism to come.

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Competing Interests

The authors have no competing interests to declare.

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