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Pathways of disability-based discrimination in cancer care

Abstract

Disabled people often report poorer health outcomes and increased barriers to accessing healthcare, compared to the general population. Our aim was to foreground lived experiences of disability-based discrimination, often indirect, and identify pathways through which this operates. We used a case study approach to explore the experiences of people with physical impairment accessing cancer services in England and Wales, from screening to therapy and follow-up, and investigated the complex and interacting nature of factors that affect their experiences. Participants described how they had to navigate a healthcare system that often was not responsive to their needs, leading to poor experiences of care. The barriers experienced by the participants operated at different levels. We identify three specific pathways through which discrimination is embodied: normativity expectations, lack of disability-awareness, and discontinuity of care. Our study is of particular importance to health professionals and policy makers, since there is limited evidence available on how people with physical impairment in the United Kingdom experience access to cancer care services. We argue that in order to advance the conversation on healthcare access for disabled people, it is important to reconceptualise the observed barriers as disability-based discrimination, reflective of broader structural processes, and to analyse in depth the pathways through which this discrimination operates.

Keywords

Access to healthcare; cancer; disabled people; health inequities; discrimination; UK

Introduction

There is evidence that disabled people embody structural disadvantage, such as increased rates of unemployment and poverty and lower education, leading to poor health (Krahn, Klein Walker, & Correa-de-Araujo, 2015). Disabled people experience poorer health outcomes, increased barriers to accessing healthcare, and reduced utilisation of preventive services, compared to the general population (Iezzoni, 2011; Sakellariou & Rotarou, 2019). Emerson et al. (2009) argued that health disparities for disabled people are the product of both direct and indirect discrimination that combined lead to compromised access to healthcare systems and to living conditions associated with poor health, while Krahn, Klein Walker, and Correa-de-Araujo (2015:S198) referred to disabled people as an '*unrecognised health disparity population*', arguing that disability is often overlooked both in health policy and in research on health access.

Access to healthcare is a multifaceted issue. For services to be accessible, they need to be available, affordable, relevant, physically accessible, and acceptable to service users (Levesque, Harris, & Russell, 2013). There is increasing evidence that disabled people face problems in several of these dimensions, with cost and physical inaccessibility being often cited as barriers to healthcare access (Hashemi, Kuper, & Wickenden, 2017; Kirschner, Breslin, & Iezzoni, 2007; Sakellariou & Rotarou, 2017a; Shakespeare, Bright, & Kuper, 2018). Neoliberal policies, such as health budget cuts, linked to the increasing use of financial indicators to measure the success of healthcare systems, can also affect access to healthcare (Sakellariou & Rotarou, 2017b).

Evidence suggests that disabled people are less likely to be screened for cancer (e.g. Floud et al., 2017; Sakellariou & Rotarou, 2019). Discomfort, inaccessibility, lack of information, and cost have been found to act as barriers to accessing cancer services (Iezzoni, Kilbridge, & Park, 2010; Llewellyn, Balandin, Poulos, & McCarthy, 2011; Merten, Pomeranz,

King, Moorhouse, & Wynn, 2015), and negative experiences might lead disabled women to skip screening procedures (Liu & Clark, 2008). Liu and Clarke (2008) found that disabled women were less likely to have mammography and Pap test explained to them compared to women without disabilities, and more likely to report problems with these procedures. Such barriers are linked to social disparities in cancer care, which arise from “*adverse working and living conditions and inadequate health care (...) and discrimination*” (Krieger, 2005:7).

These barriers in access to cancer services and the ensuing inequities contradict several United Kingdom (UK) policy documents, such as *Achieving World-Class Cancer Outcomes: a Strategy for England 2015-2020* (Independent Cancer Taskforce, 2015) and the *Cancer Delivery Plan for Wales* (Welsh Government, 2017), which both call for reducing inequalities in access to cancer services. These barriers also contravene the Equality Act (HM Government, 2010) and the Convention on the Rights of Persons with Disabilities (United Nations, 2006), which call for the elimination of barriers that affect disabled people’s participation in social life.

While we know that people with physical impairment and disabled people in general face increased barriers in accessing cancer services, there is limited evidence from the United Kingdom (a country with universal and free coverage, at the point of access) of how people with physical impairment experience access to cancer care services.

Conceptualising disability

Shakespeare, among others (e.g. Marks, 1999), has argued for a conceptualisation of disability as an ‘*interaction between individual and structural factors*’ (2013:55), calling for a critical model of disability that examines the multiple interactions of biology and structural factors. This model resonates with the International Classification of Functioning, Disability, and Health (WHO, 2001), which conceptualises disability as emerging at the intersections of

contextual and personal factors, and health conditions. This conceptualisation of disability as the outcome of a dynamic interaction is closely related to the ecosocial approach (Krieger, 2012), which considers the interaction of micro- and macro-level factors that profoundly shape the health of individuals and social groups. Linking social factors such as age, gender, and disability status with environmental influences, an ecosocial approach can offer a useful analytical tool to examine the complex interactions that create bodily and social vulnerabilities. These factors are not readily isolated, but instead overlap with and embed into one another to profoundly influence people's experience of illness, leading to what Manderson and Warren (2016) called *recursive cascades of chronicity*.

Guided by this conceptualisation of disability as a dynamic interaction between contextual and personal factors, in this article we use a case study approach to explore the experiences of cancer care access of people with physical impairment, taking into account the complex and interacting nature of factors that might affect participants' experiences. Our aim is to foreground lived experiences of disability-based discrimination, and identify pathways through which such discrimination operates.

Methodology

The cases reported in this article come from the Challenges of Cancer and Disability Study (CoCaDS), which explored cancer care experiences of people with physical impairment in England and Wales (Sakellariou et al., 2019). The study was approved by the School of Healthcare Sciences Research Ethics Committee, Cardiff University and the NHS Research Ethics Committee.

Participants were recruited via several routes, including cancer charities' notice boards (e.g. MacMillan Voices) and disabled people's organisations. Prospective participants were eligible if they: a) had undergone cancer treatment, and were in remission or 6 months

beyond treatment given with curative intent, or were the significant other of a person with such a diagnosis; b) had a pre-existing physical impairment (which in this study did not include sensory impairment); and c) were adults. Eighteen people took part in the study; ten women and eight men.

Data were collected via 23 semi-structured interviews, which lasted between 30 and 75 minutes. Using the concept of *information power* (Malterud, Siersma, & Guassora, 2016), data collection stopped when no new information was emerging. Each interview started with a general question, inviting participants to share their experiences. Subsequent questions took the form of probing questions, seeking to gain more in-depth information. Participants were also asked about themes that emerged from the literature, such as having their needs recognised and respected by healthcare professionals.

Data analysis

We utilised an iterative thematic analysis, both within and across cases, looking for cross-links between participants and alternative explanations for the emerging themes. The initial coding was discussed with the research team, which consisted of a steering committee including three healthcare professionals and two lay members (disabled people who had had cancer). Coding was conducted by two researchers (DS and SA), with backgrounds in disability and cancer research, who read and analysed all transcripts separately and met often to discuss the emerging themes.

We carried out follow-up interviews with five participants to clarify specific issues that emerged during the analysis. We used an instrumental case study design (Stake, 2005) to further analyse the complete data-set for these five participants and provide an in-depth exploration of disability-based discrimination pathways in cancer care. These five participants, four persons with a physical impairment and one partner of a person with a physical impairment, are the five cases studies presented here. These cases were purposively

selected for their depth of information and their variation, in terms of experiences, gender, and positionality and because they exemplified several of the pathways through which disability-based discrimination operates, thus contributing to a better understanding of the experiences of disabled people, or their partners/ informal carers, as they access cancer care.

Findings

The findings are presented in the form of five short stories, each representing a case study on experiences of seeking cancer services while disabled. While the findings are presented as discrete case studies in order to analyse specific issues in-depth, most of the participants experienced several of the issues discussed.

Claire: 'Look, something's really wrong'

Claire was a woman in her late fifties, living with mobility impairment as a result of a series of conditions, which included fibromyalgia, peripheral neuropathy, and back pain. Despite the difficulties these posed in her everyday life, especially pain, Claire had learnt to live with these conditions and knew what to expect of them. When new symptoms started to appear, Claire described how her general practitioner attributed them to her pre-existing conditions.

When I started with the symptoms of my cancer, which was ovarian cancer, the doctors put it down to just aches and pains that you get with those other conditions (...) I kept going back saying "Look, something's really wrong, I'm getting bigger and bigger around the stomach".

According to Claire, several healthcare professionals attributed the initial symptoms of ovarian cancer to the chronic conditions she was living with, leading to a 9-month delay from Claire noting the first symptoms of ovarian cancer to finally being diagnosed. Although she

kept on going to the general practitioners, insisting that something was not right, she reported having her concerns continuously dismissed. While ovarian cancer is notoriously difficult to diagnose due to the lack of specificity of symptoms (Bankhead, Kehoe, & Austoker, 2005), Claire felt that her health providers seemed to focus on her impairment and chronic conditions for an explanation of her bodily signs despite the recency and intense disruption of those symptoms. For example, towards the last few months prior to diagnosis she was in such pain that she had to use crutches. Feeling that healthcare professionals were not acting on her concerns, Claire reported that: *'I thought I'm dying and nobody's listening to me, nobody's doing anything about it'*.

Having her concerns dismissed, Claire felt effectively excluded by the healthcare system. She felt she was not treated as a credible witness to her own symptoms, which were consistently attributed to her pre-existing conditions, and, thus, nothing out of the ordinary. Being several years past the menopause, it was only when she started spotting blood and then started experiencing what she described as *'full blown periods, really heavy'*, her general practitioner worried that it might indeed be cancer and referred her for more tests, and:

They finally realised I had a massive tumour, which they had failed to spot, a three and a half stone tumour.

In Claire's story, disability became an essentialising category, overshadowing any other possible explanation for her symptoms. Her own ability to know which symptoms related to her impairment did not appear to be listened to, exemplified in healthcare interactions where her explanation of her symptoms was dismissed. Ultimately, the interaction between her position as a disabled woman and the reported attitudes of healthcare professionals contributed to a long diagnostic delay.

Anna: 'Everyone was just focused on the cancer'

Anna was a woman in her forties, living with multiple sclerosis. When she was diagnosed with breast cancer, it was decided she should undergo a mastectomy. As she was led to the operating theatre, she was told by the anaesthetist, for the first time, that nobody knew how anaesthesia would affect the progress of the multiple sclerosis:

[I was informed] just as they were putting the drugs into my arm. Yeah...which I thought was a bit late, they should have said that earlier on.

The way the information was delivered, in the operating theatre, when Anna could not meaningfully process and discuss the information, and at a point when she felt she could not make a decision not to proceed with the surgery, made this a very stressful moment for her. As it turned out, Anna came to in the recovery room to discover that she was paralysed and could not even speak. Lying down, unable to communicate with anyone, she was afraid that this might be a relapse in the multiple sclerosis or, even worse, a permanent change. This was not the case and she eventually regained movement a few hours later. Soon after, she had another surgery to remove tumours from the lymph nodes. That time, however, she came to after surgery to find out that she had had a relapse, losing some of the mobility and requiring her to use a wheelchair. Anna described that it was only then, after the second time that a problem arose following anaesthesia, that the multiple sclerosis and cancer teams liaised with each other.

Anna experienced aggravated multiple sclerosis-related symptoms on both occasions she had surgery for cancer. Despite the anaesthetists in both operations reportedly being aware of Anna's diagnosis, Anna felt they were not sure how she would be affected by anaesthesia. This highlights broader structural issues, especially linked with lack of continuity of care.

The separation of the two teams appeared to be so complete, that Anna almost seemed to be taking the blame herself for the effects of the lack of continuity of care, observing that *'it didn't even occur to me that the anaesthetic would affect the MS [multiple sclerosis]'*. In fact, on several occasions, Anna described her experience as good: *'Well, I mean the whole thing, experience is good in terms of the care that's provided'*.

Anna's story shows that it is not enough for services to be appropriate for a specific disease; they need to take into account both impairment and cancer and how these interact. Lack of continuity of care was exemplified in Anna's story by services working separately, with limited information about how treatment for cancer could affect multiple sclerosis. Of particular concern in Anna's story was the way she received information about the likely impact of cancer treatment on the progress of her multiple sclerosis; rather than discussing in a consultation so she had choices, Anna reports being given this information in the operating theatre, as she was being injected with the anaesthetic, turning her into a mere witness to the care she received, rather than an active participant. While perhaps nobody could have predicted or prevented the exact impact anaesthesia could have on Anna, the potential adverse interaction between multiple sclerosis and anaesthesia has been acknowledged for almost two decades, with significant literature available (e.g. Dorotta and Schubert, 2002).

Linda: 'I knew there were things wrong but we didn't know what it was'

Linda was the wife and informal carer of Robert, both in their early seventies. Robert lived with tetraplegia, the result of a high-level complete lesion in his spinal cord caused by an accident, and had no feeling below the level of the lesion, in the chest area. When he started passing blood in his urine, they both became quite concerned. Their concern, however, was initially not shared by their general practitioner, and it was several months before they were referred to a urologist at a spinal injuries unit. There, Robert was quickly diagnosed with

bladder cancer and had his bladder removed. Throughout his hospitalisations, both right after surgery and in subsequent instances, they felt professionals were not always prepared to manage Robert's needs. For example, Linda stated:

And on a colorectal ward it wasn't possible to find anybody that was prepared to do a manual bowel evacuation, which is what a high-level spinal injury patient needs. (...) And that's something that should ... it should have been possible for that to happen on the ward.

The reasons for the reported unpreparedness are unknown; whatever the reason may have been, this put extra pressure on Linda as she had to carry out the procedure herself. On a separate occasion, Linda reported how after she had explicitly instructed hospital staff to put on pressure boots on Robert, this was not followed through:

They didn't put them on him. I left him on the admissions ward at sort of midnight-ish and went home, just as he was getting into bed. And they didn't put the pressure boots on him. And by the time I got there the following day, he'd got a significant pressure sore on his heel that took weeks and weeks and weeks to heal.

When, a few months later, he started having bowel problems, they experienced a lack of coordinated care to explore the reasons behind these issues. Linda reported insisting that these problems were not typical for him. On several occasions, professionals asked Robert about the kinds of symptoms he felt in his abdomen. Robert, of course, had no sensation in any part of his body below the chest. With the cancer team and the spinal injuries team not liaising, Linda and Robert were left in a very difficult situation, where they knew things were not right but did not know how to make them better. Robert started accumulating fluid in his abdomen,

and this had to be drained three times, but still Linda reported there was no further exploration to find out the underlying reasons. As Linda said:

It was just the failure of people to join up dots and we didn't know what dots needed joining up. I knew there were things wrong but we didn't know what it was. And I think, you know, we should have been able to rely on the medical professionals to say "actually do you know what, I don't understand what's going on here (...), because I don't know anything about spinal cord injury and I've got somebody presenting who can't tell me about [their] abdominal symptoms".

Eventually, it was found out that the fluid in Robert's abdomen was connected to a recurrence of the cancer, which eventually ruptured his bowel. Robert died of sepsis, which was diagnosed at a very late stage.

Jonathan: 'Did you not notice that I've just wheeled in in a wheelchair?'

Jonathan was in his fifties at the time of the interview and he was a wheelchair-user. He was diagnosed with cancer when he was only a few weeks old. While this was successfully treated, Jonathan has been monitored for cancer ever since. When he was 15 years old his spine collapsed, potentially, according to Jonathan, due to a spine malformation as a result of radiotherapy and chemotherapy at a young age. This meant that for over 30 years, Jonathan had been accessing cancer services as a wheelchair user.

Over many years of contact with cancer services, Jonathan encountered physical inaccessibility and lack of awareness of disability by healthcare professionals. For example, once going for a magnetic resonance imaging (MRI) scan, he described the lack of experience of the healthcare professionals to care for a wheelchair user. Not knowing how to

adequately respond to the situation, Jonathan reported that healthcare professionals ‘*were panicking*’, due to the presence of a metallic object (i.e. the wheelchair) in the MRI room.

On another occasion, he needed to have a voiding cystourethrogram (a procedure which requires the insertion of a dye in the bladder) to check whether he had bladder cancer. He reported that the healthcare professionals involved in his care realised that it was not possible to perform the procedure the way they often did, by asking people to stand up, only after they had already started. Ultimately, the test could not be carried out and no option to reschedule was offered. In Jonathan's words:

And it was sort of like “did you not notice that I’ve just wheeled in in a wheelchair, did you not notice that I transferred using my arms?”. And it was like “well, we can’t do it any other way”. And it’s like, “well, then surely you should have spotted that before putting me through all this. Because now all I have to do is get back out into my chair, go to the toilet, and urinate out all this dye that you’ve wasted on me”. And I still haven’t had that test.

What was disturbing for Jonathan in the experience highlighted in the quote above, and in several other similar experiences, is that there were solutions to these problems (e.g. an urethrogram can take place from a lying position), but these solutions were not always pursued.

Matt: ‘Each little problem complicates the others’

Matt was a man in his fifties living with chronic back pain and mobility impairment due to a spinal injury. In the first few minutes of the interview, he narrated a story with many turning points. First, there was the traffic accident in which he injured his spine. This led to debilitating pain and mobility problems, and eventually to him being out of the job market.

So he decided to set up his own business but he was diagnosed with oesophageal cancer a few weeks into this new venture. This led to new problems: his back pain was sometimes very intense and when this happened he had to spend long periods in bed. But, since cancer treatment, which included an operation to remove the oesophagus and part of the stomach, he found it very difficult to lie down flat because: *'bile runs up into the back of my throat and then I start coughing'*. Accessing healthcare services after the operation, he often found that he not only had to explain his needs to people, but also to justify them. Talking about a recent visit to a hospital, Matt recounted:

They [healthcare professionals] said, "is there any problem with you laying flat?", "yes", "what do you mean yes? Nobody has a problem lying flat" "I do, I haven't got a stomach, I can't lay flat". So, yeah, these problems do have knock on effects on other things and make further problems.

Matt had not been able to get a job for many years. He relied on Employment and Support Allowance (ESA), which is a state-funded benefits scheme for people who are unable to work. The maximum amount that can be received via this scheme is 110 pounds a week. However, he was not eligible for other forms of support:

Especially now, because I can walk 20 yards I am not eligible for PIPs [personal independence payment], although the assessors do lie on their forms. Because when it came back, some of the stuff on there wasn't at all what I had said. But I don't ... I was on DLA [disability living allowance] for care and mobility. I don't get any of that now (...). The cold weather next week is going to be critical, because it will cost 60 pounds a week to heat this place. And that's half my money, so things are very, very tight under the present government.

Matt was living simultaneously with the effects of a spinal injury and the after-effects of cancer treatment in a social environment that he found to be unresponsive to his needs. It was not any one of those things in isolation, but their cumulative effect that impacted on his experience of living with cancer; in other words, he was rendered as disabled through the cumulative embodiment of various types of discrimination, ranging from poor understanding of his needs to unemployment and poverty. As he said: *'the total becomes greater than the sum of its parts ... each little problem complicates the others'*. Matt's story highlights the complexities and interacting factors related to pre-existing impairment and cancer. Even when access to cancer services in itself might not be challenging, there may be other factors affecting people's experiences, such as poverty.

Discussion

Reconceptualising barriers to cancer care as disability-based discrimination

The case studies presented show the various ways that participants in this study engaged with services. The findings indicate that sometimes people with physical impairment need to navigate a healthcare system that often demonstrates lack of awareness of disability, a system that sometimes does not even seem to acknowledge the existence of disability, and that appears to be inadequately equipped (in terms of knowledge/awareness /resources/equipment) to meet needs arising at the intersections of disability and cancer.

We argue that the barriers we have identified in healthcare access for disabled people can be conceptualised as disability-based discrimination, pointing to *'a structural effect of physical and social environments on utilisation of services by individuals'* (Levesque, Harris, & Russell, 2013:7). Such discrimination reflects structural processes where widespread policies, procedures, attitudes, and behaviours disproportionately affect disabled people (Deal, 2007; Emerson et al., 2009). These processes can be expressed, for example, by inadequate

preparation to think alternative ways to carry out cancer screening procedures and by discontinuity of care. Although people in the UK might enjoy legal protections from disability-based discrimination (HM Government, 2010), findings from this and other studies (Shakespeare, Bright, & Kuper, 2018) suggest they experience multifaceted de facto discrimination, leading to compromised access to healthcare (Sakellariou and Rotarou, 2017a; 2019). Findings from this study have added to our understanding of the experiences of disabled people as they access cancer care. We identified three specific pathways through which disability-based discrimination is embodied – normativity expectations, lack of disability-awareness and/or training, and discontinuity of care – and used detailed case studies to discuss these pathways.

Normativity expectations. Several of the interactions with healthcare services shared by the participants point to aggressions towards their dignity and right to receive appropriate care, by having their disability-related needs ignored. This was exemplified by Jonathan's experience of being expected to stand up to undertake a cancer screening procedure designed with specific bodies (i.e. those that can stand up unaided) in mind. Participants shared stories of normativity expectations where they were expected to act *like everyone else*, and made to feel culpable when they did not. This is linked to a discourse of constructing disability and its effects as a personal issue, and thus an individual responsibility; disabled people are rendered not only responsible for the care they receive but also for the bodies they inhabit and the identities they embody. Equipment and clinical procedures were often not adapted to meet the needs of the participants with physical impairment. As Read, Williams, Heslop, Mason-Angelow, and Miles (2018), report, disabled people do not always receive the healthcare services they need due to a disregard of their needs and an assumption of normative bodies, bodies that behave, move, and operate in the same way. This is an example of ableism, a form of disability-based discrimination that promotes an able-centric view, whereby tasks of

daily living are expected to be accomplished in a *normal way*; ‘*disability represents a deviation from these norms*’ (Keller & Galgay, 2010:242), and thus it conflicts with these expectations of normality.

Lack of disability awareness. The second pathway we identified is the lack of awareness of disability by healthcare professionals. Our findings align with those of Llewellyn et al. (2011), who identified lack of knowledge of disability among healthcare professionals as one of the barriers people face when they seek to access cancer services, leading to substandard experiences. Lack of disability awareness can often be seen in the lack of preparation by healthcare systems to address the needs of disabled people, which was reported by several of the participants. Analysing the ways disabled people negotiate the social practices of hospitals, Read et al. (2018) argue that in the absence of widespread disability awareness, it often becomes the responsibility of disabled service users to alert healthcare professionals to their needs; thus, disabled people need to be active patients, shaping their own care, compensating for the lack of disability awareness. They mobilise several strategies to do this: they find out what options are available, choose the ones that are best for them, and advocate for their choices to be followed. In other words, sometimes they need to do the groundwork that could reasonably be expected of a healthcare provider, while coping with a cancer, or other, diagnosis and its associated exigencies.

Discontinuity of care. Den Herder-van der Eerden et al. (2017) argue that people living with cancer often experience a lack of coordination between the different clinicians involved in their care. Disabled people are especially exposed to this discontinuity of care, because they are often observed by one team for their impairment and by a separate one when something new emerges, such as cancer. Lack of coordination between the different teams can lead to discontinuity of care (Haggerty et al., 2013).

It is important to note that these pathways operate within a context of pervasive subtle prejudice against disabled people (Deal, 2007) and broader barriers that this study only touched upon. Jonathan's story, for example, illustrated how the barriers he experienced were not only linked to interactions with healthcare professionals, where his needs were not understood, but also to a lack of resources and/or flexibility in service provision to make it inclusive and accessible. Structural forces themselves shape the interpersonal, from the limited/non-existent training around care for disabled people that health practitioners receive, to the time pressures placed on consultations.

While our findings demonstrate that disability-based discrimination is linked to experiences of substandard care, we need to point out that often, although not always, participants in this study were reluctant to either characterise the care they received as poor or to attribute blame to specific individuals. Dissociating the care that was provided to them from the people who provided it and justifying poor care as a consequence of systemic failures that could not be attributed to individuals, meant that several participants expressed generalised gratitude for substandard, and sometimes dangerous, care. Such gratitude becomes possible '*by rationalising or justifying the poor service with reference to general welfare problems, including austerity, a lack of personnel or time*' (Bradby, Humphris, & Padilla, 2018:5-6). Within this context, however, disabled people might be even more reluctant to seek the services they need or make a complaint about substandard care, fearing they might get characterised as undeserving, needy, or ungrateful patients. We recognise that some of the issues described (for example, general practitioners not referring early enough for further tests) may not be uncommon among the general population. This research suggests that the impact of these issues may be magnified for disabled people because, for example, symptoms may be misdiagnosed as being related to pre-existing impairment, leading to diagnostic delays.

We do not suggest that healthcare professionals do not strive to provide care of a high standard to their patients, nor that all disabled patients receive substandard care. Instead, we contend that the pathways through which disability-based discrimination is embodied indicate structural failings of healthcare systems. Such failings expose the practical challenges of implementing legislation which was designed specifically to address disability-based discrimination (among other forms of discrimination). The Equality Act 2010 (HM Government, 2010) identified disability as a protected characteristic and established disability-based discrimination as an offence, entitling people to what is termed as *reasonable* adjustments to meet their needs. Yet, as our findings demonstrate, these adjustments are not always implemented in the context of healthcare.

In their report to the UN Special Rapporteur on the rights of disabled persons, Shakespeare, Bright, and Kuper (2018) highlighted that this population faces many barriers to healthcare access and often their right to good quality healthcare is not realised. Reporting on the implementation of the United Nations Convention on the Rights of Persons with Disabilities in the UK, the Committee on the Rights of Persons with Disabilities observed the existence of

systemic, physical, attitudinal and/or communicative barriers preventing persons with disabilities from accessing mainstream health services including: inaccessible furnishing, training and treatment equipment, medicine and supplies, means of information and communication, limited access to clinics and healthcare professionals, hospitals, dentists, gynaecologists and obstetricians (2017:no page).

It is important to take into account that these barriers to accessing healthcare happen within a broader context of marginalisation from social life and cumulative disadvantage for disabled people. We concur with Krieger (2012:942) that while data showing discrimination are not

enough to rectify inequities, *'the absence of data demonstrating harm nevertheless is itself harmful'*. It is therefore important to invest research efforts in examining disability-based discrimination in healthcare and how it affects both access to care and health outcomes. It is particularly urgent to invest efforts in improving access to healthcare for disabled people, considering the policy, the service organisation, and the service delivery levels (Shakespeare, Bright, & Kuper, 2018). Strategies that could help include disability training for healthcare students and professionals, raising visibility of disabled people's needs, ensuring health facilities and equipment are accessible, and improving continuity of care (through, for example the use of patient-held records). It is also important to monitor the inclusion of disabled people in healthcare, in order to identify gaps in access and / or provision of services and the underlying factors (Shakespeare, Bright, & Kuper, 2018). Most crucially, what is needed is an organisational and cultural shift to respect disabled people's fundamental right to healthcare.

Conclusions

We have foregrounded lived experiences of disability-based discrimination and identified three pathways of embodiment of such discrimination in relation to accessing cancer services: normativity expectations, lack of disability awareness in health services, and discontinuity of care. We found that participants faced a variety of barriers to access that should be conceptualised as disability-based discrimination. These barriers are structural, cumulative, and interactional in nature, and produce disadvantage in people's lives. Discrimination operates at different levels, ultimately compromising disabled people's access to healthcare. While this study focused on cancer care, it is reasonable to assume that disability-based discrimination occurs across other health services.

The clinical encounter – that direct contact between patient and professional – is a main arena where discrimination such as the invisibilisation of needs, or harm by neglect, are experienced. Discrimination is also experienced at the broader, systemic level, when, for example, needs arising from the interaction of cancer and impairment are not taken into account by health and social support systems. The cumulative effects of these processes can lead to a violation of disabled people’s right to quality healthcare.

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References

- Bankhead, C. R., Kehoe, S. T., & Austoker, J. (2005). Symptoms associated with diagnosis of ovarian cancer: A systematic review. *BJOG: An International Journal of Obstetrics & Gynaecology*, *112*(7), 857-865.
- Bradby, H., Humphris, R., & Padilla, B. (2018). Universalism, diversity and norms: Gratitude, healthcare and welfare chauvinism. *Critical Public Health*. doi: <https://doi.org/10.1080/09581596.2018.1522420>
- Committee on the Rights of Persons with Disabilities. (2017). Concluding observations on the initial report of the United Kingdom of Great Britain and Northern Ireland. Retrieved 14 August 2018, from https://tbinternet.ohchr.org/_layouts/treatybodyexternal/SessionDetails1.aspx?SessionID=1158&Lang=en
- Deal, M. (2007). Aversive disablism: Subtle prejudice toward disabled people. *Disability & Society*, *22*(1), 93-107.
- Den Herder-van der Eerden, M., Hasselaar, J., Payne, S., Varey, S., Schwabe, S., Radbruch, L., Van Beek, K., Menten, J., Busa, C., Csikos, A., & Vissers, K. (2017). How continuity of care is experienced within the context of integrated palliative care: A qualitative study with patients and family caregivers in five European countries. *Palliative Medicine*, *31*(10), 946-955.
- Dorotta, I. R., & Schubert, A. (2002). Multiple sclerosis and anesthetic implications. *Current Opinion in Anesthesiology*, *15*(3), 365-370.
- Emerson, E., Madden, R., Robertson, J., Graham, H., Hatton, C., & Llewellyn, G. (2009). *Intellectual and Physical Disability, Social Mobility, Social Inclusion & Health*. Center for Disability Research, Lancaster University. Retrieved 14 February 2019, from

http://eprints.lancs.ac.uk/26403/1/Disability_Social_Mobility_Social_Inclusion.pdf

Floud, S., Barnes, I., Verfürden, M., Kuper, H., Gathani, T., Blanks, R. G., Alison, R., Patnick, J., Beral, V., Green, J., & Reeves, G. K. (2017). Disability and participation in breast and bowel cancer screening in England: A large prospective study. *British Journal of Cancer*, *117*(11), 1711-1714.

Haggerty, J. L., Roberge, D., Freeman, G. K., & Beaulieu, C. (2013). Experienced continuity of care when patients see multiple clinicians: A qualitative metasummary. *The Annals of Family Medicine*, *11*(3), 262-271.

Hashemi, G., Kuper, H., & Wickenden, M. (2017). SDGs, inclusive health and the path to universal health coverage. *Disability and the Global South*, *4*(1), 1088-1111.

HM Government (2010). *Equality Act 2010*. London: The Stationary Office.

Iezzoni, L. I. (2011). Eliminating health and health care disparities among the growing population of people with disabilities. *Health Affairs*, *30*(10), 1947-1954.

Iezzoni, L. I., Kilbridge, K., & Park, E. R. (2010). Physical access barriers to care for diagnosis and treatment of breast cancer among women with mobility impairments. *Oncology nursing Forum*, *37*(6), 711- 717.

Independent Cancer Taskforce. (2015). Achieving world-class cancer outcomes: A strategy for England 2015-2020. Retrieved 21 October 2018, from <https://www.england.nhs.uk/publication/achieving-world-class-cancer-outcomes/>

Keller, R.M., & Galgay, C.E. (2010). Microaggressive experiences of people with disabilities. In Sue, D.W. (ed.) *Microaggressions and Marginality: Manifestation, Dynamics, and Impact*. Hoboken, New Jersey: John Wiley & Sons.

Kirschner, K. L., Breslin, M. L., & Iezzoni, L. I. (2007). Structural impairments that limit access to health care for patients with disabilities. *JAMA*, *297*(10), 1121-1125.

Krieger, N. (2005). Defining and investigating social disparities in cancer: Critical issues.

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Cancer Causes & Control, 16(1), 5-14.

Krieger, N. (2012). Methods for the scientific study of discrimination and health: An ecosocial approach. *American Journal of Public Health*, 102(5), 936-944.

Krahn, G. L., Walker, D. K., & Correa-De-Araujo, R. (2015). Persons with disabilities as an unrecognized health disparity population. *American Journal of Public Health*, 105(S2), S198-S206.

Levesque, J. F., Harris, M. F., & Russell, G. (2013). Patient-centred access to health care: Conceptualising access at the interface of health systems and populations. *International Journal for Equity in Health*, 12(1), 18. doi: <https://doi.org/10.1186/1475-9276-12-18>

Liu, S. Y., & Clark, M. A. (2008). Breast and cervical cancer screening practices among disabled women aged 40–75: Does quality of the experience matter? *Journal of Women's Health*, 17(8), 1321-1329.

Llewellyn, G., Balandin, S., Poulos, A., & McCarthy, L. (2011). Disability and mammography screening: Intangible barriers to participation. *Disability and Rehabilitation*, 33(19-20), 1755-1767.

Malterud, K., Siersma, V. D., & Guassora, A. D. (2016). Sample size in qualitative interview studies: Guided by information power. *Qualitative Health Research*, 26(13), 1753-1760.

Manderson, L., & Warren, N. (2016). “Just one thing after another”: Recursive cascades and chronic conditions. *Medical Anthropology Quarterly*, 30(4), 479-497.

Marks, D. (1999). Dimensions of oppression: Theorising the embodied subject. *Disability & Society*, 14(5), 611-626.

Merten, J. W., Pomeranz, J. L., King, J. L., Moorhouse, M., & Wynn, R. D. (2015). Barriers

to cancer screening for people with disabilities: A literature review. *Disability and Health Journal*, 8(1), 9-16.

- Read, S., Williams, V., Heslop, P., Mason-Angelow, V., & Miles, C. (2018). Being a disabled patient: Negotiating the social practices of hospitals in England. *Social Inclusion*, 6(2), 74-82.
- Sakellariou, D., Anstey, S., Gaze, S., Girt, E., Kelly, D., Moore, B., Polack, S., Pratt, R., Tyrer, G., Warren, N., Wilkinson, W., Courtenay, M. (2019). Barriers to accessing cancer services for adults with physical disabilities in England and Wales: an interview-based study. *BMJ Open*, 9(6), e027555. doi: 10.1136/bmjopen-2018-027555
- Sakellariou, D., & Rotarou, E. S. (2017a). Access to healthcare for men and women with disabilities in the UK: Secondary analysis of cross-sectional data. *BMJ Open*, 7(8), e016614. doi: 10.1136/bmjopen-2017-016614
- Sakellariou, D., & Rotarou, E. S. (2017b). The effects of neoliberal policies on access to healthcare for people with disabilities. *International Journal for Equity in Health*, 16(1), 199. doi: [10.1186/s12939-017-0699-3](https://doi.org/10.1186/s12939-017-0699-3)
- Sakellariou, D., & Rotarou, E. S. (2019). Utilisation of mammography by women with mobility impairments in the United Kingdom: A secondary analysis of cross-sectional data. *BMJ Open*, in press. doi: 10.1136/bmjopen-2018-024571
- Shakespeare, T. (2013). *Disability Rights and Wrongs Revisited*. London: Routledge.
- Shakespeare, T., Bright, T., & Kuper, H. (2018). Access to health for persons with disabilities. Retrieved 14 August 2018, from https://www.ohchr.org/_layouts/15/WopiFrame.aspx?sourcedoc=/Documents/Issues/Disability/StandardHealth/BackgroundDoc_EGM_Righttohealth.docx&action=default&DefaultItemOpen=1

Stake, R. (2005). Qualitative case studies. In Denzin, L., & Lincoln Y. (eds.) *The SAGE Handbook of Qualitative Research, 3rd ed.* Thousand Oaks: Sage.

United Nations. (2016). *Convention on the Rights of Persons with Disabilities*. Retrieved 22 February 2019, from <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>

Welsh Government. (2017). *Cancer Delivery Plan for the NHS to 2020*. Cardiff: Author.

World Health Organization. (2001). *International Classification of Functioning, Disability and Health: ICF*. Geneva: World Health Organization.

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