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Eva Duda-Mikulin & Marta Głowacka

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'We are all disabled': one British Pakistani man's struggle navigating his hybrid identities

Eva Duda-Mikulin ^a and Marta Głowacka ^b

^aUniversity of Wrocław, Wrocław, Poland; ^bIndependent Researcher, Poland

ABSTRACT

The case study of Alex that we explore in this paper broadens our knowledge about the notions of ethnicity and disability and their interplay for one British Pakistani man with a diagnosis of epilepsy and his everyday life in Britain. This paper presents indicative findings and qualitative insights based on lived experience, which is particularly valuable for identity-related research. We offer a review of the existing literature around disability, ethnicity, hybrid identity, and South Asian perception of disability and impairment. We provide a note on methodology, including a case study design and thematic analysis, together with participant demographic details.

The paper contributes to contemporary debates about how South Asian men with a disability construct new forms of identity and belonging in Britain. A qualitative case study of a self-identifying British Pakistani man, who has a diagnosis of epilepsy, sought to understand how he formulated identity and employed differing practices in navigating belonging in relation to his ethnicity/migrant background on the one hand and his disability/chronic illness on the other. The findings indicate that the intersectionality of ethnicity and disability, racism, and ableism constitutes truly nuanced forms of othering and a 'hybrid identity'.

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Introduction

There is a substantial gap in existing knowledge and literature on migration and disability (Buckley et al., 2015; Burns, 2019; Duda-Mikulin et al., 2020; Duda-Mikulin & Głowacka, 2023; Hughes, 2017; Pisani & Grech, 2015; Roberts, 2000; Yeo, 2021). There is a need to unpack and explore ethnicity and disability as different parts of one's identity (Hussain, 2005; Inckle, 2015; Lopez & Xu, 2021; Parks, 2021). Intersectionality allows us to do that as it is the junctures of various elements of a person's identity that interest us. This paper aims to contribute to filling the mentioned gaps. Additionally, health-related scholarship increasingly relies on and values lived experience, and this paper offers just that (Beames et al., 2021).

CONTACT Eva Duda-Mikulin  Eva.duda@uwr.edu.pl  <https://www.linkedin.com/in/evaannaduda/>

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The case study that we explore in this paper broadens our knowledge in relation to the notions of ethnicity and disability and their interplay for one British Pakistani man with a diagnosis of epilepsy and his everyday life in Britain. To do that, in the first instance, we offer a review of the existing literature around disability and ethnicity, epilepsy, and South Asian perceptions of disability and impairment. We then provide a note on methodology, including a case study design and thematic analysis, together with participant demographic details. The penultimate section details the discussion of the findings. The paper ends with conclusions, including limitations and directions for future research.

Disability and ethnicity

Disabled people are considered the largest minority in the world, representing approximately 15% of the world's population, with the proportion expected to increase as the world's population ages (Mosler Vidal, 2022). Given that both migrant and disabled people face barriers to social and economic participation, disabled migrants may face double or triple disadvantages when confronting racial or ethnic discrimination, language barriers, ableism, and other systemic processes. Migrants with disabilities may become multiply marginalised (Duda-Mikulín & Głowacka, 2023). A non-disabled body, a normative body, and a normative ethnicity constitute a privilege.

Lopez and Xu (2021) emphasise that there is little research on epilepsy and people from ethnic minorities. As Hussain (2005) argues, little is known of commonalities and differences between disabled ethnic minority women and disabled White women. We can assume that the same can be said about the experiences of disabled ethnic minority men in contrast to disabled White men. Although issues of gender disadvantage women more than men, matters of disability and/or impairment touch on both. This paper does not intend to dispute or argue against various axes of difference and their strength or reach or hierarchy, it simply explores aspects of one individual's identity reconstruction and negotiation with regard to ethnicity and disability.

It is the convergence of multiple places and cultures that transforms the terms of South Asian men's experiences, a process which requires them to negotiate and renegotiate their identities (cf. Miles, 2001). It is against this background that this article aims to decipher questions of identity, by examining one man's experiences of the interconnected practices related to ethnicity/migrant background, family life within the South Asian community, and experiences of disability in the past and present in Britain (cf. Lejzerowicz, 2017). These practices are the focus of the empirical analysis as they are the most significant sites of the hybridisation of identity, negotiation between parents and children, and where questions of ethnicity and the meanings ascribed to the disabled body come to the fore (cf. Boland, 2000). Hybridity, when related to identity research, points to a blending of differences in such a way that new performances of identity may appear in various social interactions. Exploring hybridity can create new perceptions of social life and reveal the complex ways that people's diverse relationships and life stages construct their identities (Parks, 2021).

Yet, some scholars question the validity and usefulness of focusing on notions of identity and difference (Grossberg, 1996). Gilroy (1993) postulates that instead of separating people into narrow groups, we should look at finding innovative ways of explaining the world. Transnational significance and recognising global issues and networks should be emphasised, as ethnicity is a continuous process of identity construction.

This is while intercultural identity should be understood as exceeding national borders and ethnic classifications. Hall (1990) describes identity as a structured representation which only achieves its positive through the narrow negative eye. Meaning that the self cannot be formed in isolation and only when it comes into contact with the other does it know itself. In essence, the scholars are proposing that instead of seeing identities as fixed, isolated categories, we should view them as fluid, evolving, and shaped by ongoing interactions with others, across national and cultural boundaries. This view challenges the traditional notion that identity can be neatly defined based on ethnicity or nationality and instead suggests that identity is an ongoing process of negotiation and construction that happens in a globalised world.

While the theme of stigma, in relation to epilepsy with individuals and their families, has already been covered (see e.g. Scambler, 1989; Webster, 2018), there has been very little research on the intersections of ethnicity/migration and disability/illness which this paper aims to remedy. Ethnicity and disability are perceived as inferior categories of human beings, while whiteness and ablebodiedness are shifting categories depending on social norms, beliefs, and prejudices of the time (Inckle, 2015). However, it is noteworthy that stigma in relation to epilepsy prevalent among individuals of Pakistani origin has been diminishing (Mogal & Aziz, 2019).

Our bodies, like our emotional selves, can rarely if ever be taken for granted. Instead, they are continually problematised through a proliferation of health-related, risk-based discourses, the net result being a chronic form of bodily surveillance if not dys-appearance. (Williams, 2000, p. 60)

'Impaired' also locates the body within a medicalised framework alongside bodies that are categorised as sick and unhealthy and equates disability with weakness and incapacity. However, it is possible to be disabled and in the fullness of health, as exemplified by disabled athletes, for instance. Moreover, as Buckingham (2011) emphasised disability is as important as ethnicity as an analytic tool in the understanding of oppression and disempowerment.

Epilepsy

It remains ambiguous whether epilepsy is or is not considered a disability (Rhodes et al., 2008a). However, any condition or impairment that greatly affects one's life for a long period can be understood as such. While epilepsy is a chronic condition, it can be managed with medication. Epilepsy, as a chronic illness, can be understood as a 'critical event' (Giddens, 1979) or a 'major kind of disruptive experience' (Bury, 1982). Pain or dysfunction of the body becomes a form of 'bodily alienation' or 'betrayal' (Bury, 1982). Coping and strategic action are key processes in responding to and presenting illness or a chronic condition.

After Rhodes and colleagues (2008a, p. 385), we accept that epilepsy:

does not fit neatly within the various conceptions of disability current in popular and academic discourse. It straddles the divide between illness and impairment, disorders of the mind and disorders of the body, spiritual and biomedical paradigms.

It is noteworthy that while for some epilepsy will cause extreme physical disruption, for others, it will not be noticeable at all and thus: 'accepting a diagnosis of epilepsy does not necessarily entail accepting the label "disabled"' (Rhodes et al., 2008a, p. 386).

We recognise disability as an outcome not of bodily pathology, but of social disadvantage and oppression, which some people may have suffered as a child. This is while in later life, they may choose to 'pass as normal' if awarded this choice and in awareness of the disadvantage/s they can now leave behind. Biographical disruption carries particular class- and age-related connotations, as well as ethnic dimensions, which remain underplayed and under-researched (Williams, 2000), some of which we wish to explore below.

South Asians¹ and disability

The meaning of disability in British South Asian communities is neglected and remains poorly understood in current debates in disability studies. (Hussain, 2005, p. 536)

As Buckingham (2011) argues, the existing historical understandings of disability are dominated by European and American experience and tend to assume these are universal norms. Hussain (2005, p. 527) notes: 'The South Asian community still deploys a medical model of disability that is primarily concerned with the physical body'. Disability is often perceived as a punishment from God (Hussain et al., 2002), where feelings of resentment and rejection of the (disabled) child are not uncommon (Webster, 2018). Parents, who care for a disabled child, often become overprotective and underestimate the abilities of the child, and thus undermine their ability to exercise control over their lives (Atkin & Ahmad, 2000). Consequently, this puts a strain on the parent-child relationship. Hussain (2005) referred to a distinction between boys and girls as children and highlighted that in South Asian cultures, parents often desire boys more than girls and thus worry about girls more particularly when they are disabled.

Impairment is often perceived to be given by the chosen God² or spiritual being, who would also provide the family with the resources necessary to cope with the child's disability or impairment (Atkin & Ahmad, 2000; Lim et al., 2018). 'For some of these families, their child's impairment was associated with the sins of a previous life' (Hussain, 2005, p. 531). Hussain (2005) noted gendered differences in the treatment of children with disabilities in the sense that daughters were seen as more disadvantaged since parents would experience difficulties in marrying them. In the case of sons, however, marrying enabled a transfer of the caring role: 'parents and siblings continually referred to the partner in the role of the carer, they wanted their sons to get married so that their wives could take over the role of the carer which they had been filling' (Hussain, 2005, p. 533). Remaining unmarried was seen as inevitable for disabled daughters, whereas disabled sons could gain a lifetime carer through marriage, which is based on traditional gender roles. More recent research on the South Asian community and disability shows that parents/individuals draw on multiple cultural referents, intertwining contradictory religious, biomedical, social, and cultural explanations (cf. Lopez & Xu, 2021).

Methodology

This paper presents a case study and is based on data gathered during one in-depth semi-structured interview conducted in the interviewee's workplace in the North of England, UK, in 2019. The interview lasted over 90 minutes. Although these are not recent data, the findings remain relevant for the discussion of the topics of hybrid identity, ethnicity, migration, and illness/disability perception.

This interview was part of a larger externally funded research project looking at the intersections between migration and disability. The whole sample comprised individuals who identify as migrants, disabled people, migrants with disabilities, and key informants (for more, see: Duda-Mikulín, 2024; Duda-Mikulín & Głowacka, 2023). The findings reported here are based on a detailed analysis of one interview, as it differed in length, depth of information, and type of interviewee. The latter relates to the fact that the research participant was the only one who was a second-generation migrant. However, the other interview data also informed our analysis.

The respondent volunteered to be interviewed after an email invite was sent out to all employees who were part of a race equality forum at that particular workplace. The interview was conducted by one of the authors, recorded on an audio recorder, and transcribed verbatim by a professional transcription company. During this research project, we were guided by a number of ethical principles, including informed consent, voluntary participation, withdrawal, anonymity, and confidentiality. The study was conducted in accordance with the Declaration of Helsinki, and approved by the Chair of the Humanities, Social and Health Sciences Research Ethics Panel at the University of Bradford, UK (date of approval: 1 November 2018).

Reflexive thematic analysis was employed and guided by the new theorisation from Braun and Clarke (2021), who wrote on this topic (Braun & Clarke, 2006) and have since advanced its features and main underpinnings. Reflexive thematic analysis (RTA) is a theoretically flexible interpretative approach to qualitative data analysis that facilitates the identification and analysis of patterns or themes in a given dataset. RTA emphasises on the reflexivity of the researcher(s), theoretical independence/flexibility (without being atheoretical), and the guiding presence of the research questions. The reflexive approach to thematic analysis highlights the researcher's active role in knowledge production. RTA is considered a reflection of the researcher's interpretive analysis of the data conducted at the intersection of: the dataset, the theoretical assumptions of the analysis, and the analytical skills/resources of the researcher (Braun & Clarke, 2019). The process of coding and theme development is flexible and organic, and often evolves throughout the analytical process. Braun and Clarke (2019) encourage researchers to embrace reflexivity, subjectivity, and creativity as assets in knowledge production and postulate that RTA is particularly suitable to constructionism and is a purely qualitative approach.

The interview was analysed by both authors independently to understand the complexity of the respondent's experience as a person from an ethnic minority in the UK, who has a long-term condition, a diagnosis of epilepsy. Through discussions that followed an independent analysis, several key issues related to the topic of interest were identified and are discussed below. In our approach to analysis, we see the process as largely subjective, where the background of the researcher is important as it can, and often does, influence the process (cf. familiar stranger, Agarwal et al., 2009). Therefore, we would like to offer a reflexive note in relation to our backgrounds: one of us is a sociologist and a political scientist who has worked in the area of migration and health studies for a number of years and the other is a psychologist with experience in health research and education; we both have long-term migration experience and a keen interest in disability studies together with experience of chronic illness. Our analysis is conducted from the perspective of European researchers who were previously located in the UK but now relocated to Central Europe.

The respondent, Alex, identifies as a British Pakistani man. Alex, who chose this pseudonym himself, which is not without its significance as it demonstrates the desire to blend in with the use of gender- and ethnic-neutral names such as Alex. At the time of the interview, he was 47 years of age. His parents are first-generation immigrants who moved from Pakistan to the UK, where Alex was born. This means that Alex is a second-generation migrant to the UK. Alex is highly educated (PhD) and a professional worker in his field. Alex perceives his family to be multicultural as his wife of 25 years originates from South America. They have two teenage children. Alex was diagnosed with epilepsy and, as a child, suffered from frequent tonic-clonic seizures.³ He has not had a seizure for some years now, while epilepsy remains undisclosed outside of a very close network of family members, many of whom found out about it by chance.

In this paper, epilepsy is seen as a lifelong chronic condition not dissimilar to disability or impairments. When Alex responded to the advertisement to be interviewed for this research described as a study on disability and migration and during the interview, he himself talked about disability although it remains uncertain whether he would identify as a person with a disability even though he came forward as one for this research. That said, his perception and attitudes towards his disability are complex, as we discuss below. It is noteworthy that while Alex admitted he was hesitant as to whether to come forward and take part in this research and then whether to withdraw, do not show up to the interview, he also confessed afterwards that he enjoyed taking part and talking through these issues with a stranger. Indeed, after completing the interview, Alex sent an email to the interviewer thanking them for the opportunity to open up in a neutral space. Hence, taking part in this research appears to be a positive experience, which we take as a compliment and to reciprocate, we would like to share what we learnt from Alex.

Findings

Below, we discuss our findings from the interview with Alex, which are organised in three key themes: nondisclosure, reasoning, and being different, hybrid identity, and belonging. In the first section, we focus on events from Alex's past that influenced the way he perceives and manages parts of his identity related to disability and ethnicity/migration history. The second section explores Alex's reasoning behind (re)constructing his identity in the context of ethnicity and illness, and how these are perceived by others. The last section brings the focus onto Alex's hybrid identity, which revolves around his visible ethnicity and invisible disability and affects matters related to belonging.

Nondisclosure

So, I have epilepsy. Not many people know about that, and I had epilepsy as a child, and I'd suffer often from seizures, and I still have epilepsy, although I've not had a seizure for a long time now. And it's not something I disclose to anybody. So, my work colleagues don't know and it's not officially in my notes. It is somewhere because once you've been prescribed medication, it's somewhere, but I've not declared it or anything like this.

From the start of the interview, Alex sought reassurance that taking part in the research would not lead to disclosing his condition to a wider audience, seeking assurances of

anonymity and confidentiality. Alex actively hides his disability at home and work. This seems to have roots in his childhood when he experienced a lack of understanding around his illness, being seen as deficient in some way and discriminated against. In the interview, Alex highlighted his resentment over this as well as grief over educational and professional opportunities he thinks he had lost due to others seeing his illness as a barrier to higher achievements. Due to the successful management of epilepsy and because he has not had a seizure for some time, Alex is now able to make decisions regarding (non)disclosing his condition, and he usually chooses not to. The dysfunction of Alex's body becomes a form of 'bodily alienation' or 'betrayal' or it used to during his childhood (Bury, 1982). In the interview, it was apparent that having this choice is important for Alex as it allows him to reject the 'disabled' label and present himself as a capable professional instead. Although Alex views disability as incapacity, exposing a negative attitude, this is not always the case, and increasingly more studies emphasise a positive view of disability (Lawson et al., 2017; Swain & French, 2000).

Alex feels resentment towards his family investing resources to maintain links with Pakistan rather than pursuing a more British way of life (e.g. going on holidays abroad). Alex is also very sensitive about the sense of smell, particularly in relation to South Asian cooking, and thus he makes sure he always has a bottle of perfume at hand. These efforts show his attempts to fit in and redress the potential disadvantage arising from his ethnic origin:

Yes, and then our ethnicity impacted us a lot in that way because my parents were first-generation migrants. So, they were always pulling in that direction, they'd say everything about Pakistan. I remember that they used to buy nice things. I used to think they were for us, but they put them in the suitcase to take to Pakistan. Yes, and it's like, what the hell, we're just getting by here and we're taking presents for all those people as well. So, we were almost literally in two worlds, pulled in that direction ...

Alex refers to being 'in two worlds' when he describes his childhood in the UK, which included frequent trips to Pakistan,⁴ where his parents are from. This signifies his struggle with his ethnicity/migration history, as he seems to lack understanding as to why his parents were so drawn to their country of origin, while he was more focused on building a more British way of life.

Following Burns (2017), we recognise the need to explore the themes of disability, migration, and health. It is noteworthy that we view ethnicity and disability as social processes which inform one another, and which operate in distinct ways to form a nuanced lived experience, which we try to explore in this paper by investigating a case study of Alex. The fact that they are processes signifies that they are not static, and they change under given circumstances. Grossberg (1996), Gilroy (1993), and Hall (1990) provide a critical reflection on the concept of identity, challenging traditional ways of understanding, and categorising people based on ethnic and national lines.

Alex's lived experiences of his school years demonstrate how various processes of ethno-racial subordination coincide in particular social moments. We believe it is important to analyse ethnicity and disability as co-constitutive processes and as distinctive and historically specific technologies of categorisation. This way, intersectionality will be able to offer insights that exceed imagining these axes of difference as inextricably bound up (cf. Crenshaw, 1989).

Alex feels resentment towards the protective approach of his family, his parents in particular. This is linked to Alex's belief that they see him primarily as intellectually limited. Still, when meeting with his extended family, epilepsy is a taboo as his uncle refers to it as 'that funny thing Alex had as a child'. In this phrase, the word 'funny' should be read as strange or odd and unusual rather than referring to it humorously. Questions that are linked to concern or perhaps curiosity, such as 'how is that thing?' upset Alex as they point to an unwanted difference. He also admits that worry about a seizure could bring on a seizure. It is almost as if Alex would rather cancel the past not to have to relive it. It seems impossible for him to differentiate between genuine concern and a prejudiced one. Linked to that is his account of being perceived as 'aloof' or 'more laid-back' at work, which is another misperception of him. The non-disclosure to his family is related to a fear of change of familial relationships, whereas the non-disclosure at work is linked to a fear of othering.

Similar to Rhodes and colleagues' participants (2008b), Alex chooses to stay invisible or pass as non-disabled and ordinary. He now has the agency to do so as opposed to when he was a child and had seizures and thus no choice regarding disclosure. Now he researched it, somewhat accepted that part of his identity, but chose not to disclose it, and managed to hide it well. It is still a taboo at home. Indeed, he developed techniques of avoidance, which demonstrate the extent to which he is prepared to go to disclose his chronic condition. In order not to disclose his illness when he was referred to have an MRI to get checked, he made up another story for colleagues at work, and to keep it up, he researched the procedure in case he got asked about it:

R: I didn't [tell them], I said it was about the knee, and guess what I even did to keep up the lie? I looked up the anatomy of the knee and I learned about it just in case somebody asked me. (...) Can you believe I did that, I was like how stupid is it. So, now I know, well, a bit about the anatomy of the knee and the benefits of FMRI.

Alex did not disclose his illness to his partner until 10 years after their wedding day, and that was only because the circumstances demanded it, as he was filling out a joint application for life insurance where there was a section on health and pre-existing conditions:

R: I've been together with my wife for 25 years. (...) And I didn't even tell her for about ten years.

I: It must have been difficult to tell her, all of a sudden, after the dating years.

R: It was, but do you know what it was? Because I think we were getting life insurance or something like this, because they pull your medical records, don't they?

I: They do, yes. So, it wasn't out of your own sort of choice. So, you had to.

R: I had to. Even then I tried to hide it in some way. I tried to get her to do her bits first, and I would do the bit and I would send it.

The fact that despite having been in a committed long-term relationship he did not tell his partner about epilepsy and that even when the circumstances were such that he had to, he still sought ways to avoid 'coming out' demonstrates how deeply he cares about this, and fears a change in the way he is perceived by others, even his closest family.

Alex recognises certain socio-cultural and policy changes between the past and present which arguably should make his life easier in navigating his illness at work and

in private life (e.g. The 2010 Equality Act). He notices a change in perception and attitudes towards disability, as well as more knowledge and awareness of fluctuating conditions and also the South Asian culture. This is seen through comparisons between his childhood experiences and his sons' current encounters with difference. The decision not to disclose is upheld despite the changes he notices in the wider society. The views Alex shares and the views of his family demonstrate how these experiences are socially constructed and regulated. Still, Alex's teenage children are not aware of the fact that their dad was diagnosed with epilepsy. While Alex's wife had shown understanding and a lack of interest in it, his sons seemed interested in these matters:

R: She was, is that it, yes, yes, and I just said I'm really sorry that I didn't tell you. The boys don't know. (...) sons are 17 and 11, and then it was quite funny because my son plays in a band and everything, and he said, 'Oh, somebody had a seizure today.' The guy who comes to teach the band had a seizure, and straight away, I was like, 'And what happened?', just interviewing, like, 'Oh okay, what did you think?' He said, 'No, nothing.' He said, 'We just got a bit frightened because we didn't know what was going on, because we're young.' But in the assembly, they explained all about epilepsy to us and what happens when you have a seizure and there's nothing to be frightened about and you can't catch it and all this. And then my son said, 'Oh, you probably don't know much about this. So, I'll educate you', oh, thank you for that, and my wife is looking like hmm, okay. And I said, 'What do you think about that?' He went 'No, nothing.' I said, 'Are you going to go next week?' He said, 'Yes, of course I am.' And I interviewed him and I said, 'Do you think [man who had seizure] is any different?' And he went 'No, he is kinda.' I said, 'What do you mean?', and he went, 'Oh, he's rubbish at guitar, but he's really good on the drums.'

The above quote demonstrates how matters related to various 'differences' are taught in schools and how it is now being normalised. Alex shows acceptance of change in wider society but also in himself which resulted in greater choice and the possibility not to disclose what he seems pleased to have. Indeed, today we experience less definitive patterns of life with more work flexibility, for instance (e.g. because of the COVID-19 pandemic), and thus the experience of chronic illness or disability can potentially be less disruptive than in the past.

Reasoning/being different

When explaining his reasons for not disclosing his condition to others, categories of 'difference' as a negative and unwanted characteristic keep coming to the fore. Alex says: 'I just think people will just see you differently, and I think that's the worst thing.' Among barriers to disclosure, which we identified are: own preconceptions and worry about self-image and self-worth; exposing vulnerability versus wanting to come out (e.g. for this interview); fear of being seen as different, other, worse, less capable; and anxiety about disability clouding the image of a successful professional:

I don't know. I think people might start making ... , even the [reasonable] adjustments [as part of the Equality Act, 2010 in the UK]. Sometimes, something done in a nice way makes you out to be different. I'm different enough as it is.

Alex perceives differences as a weakness. Throughout the interview, Alex kept coming back to how he thinks that being seen as different is a bad thing while he wishes not to stand out, wants to fit in and be like everyone else. His longing to belong and fit in

is very evident. He explains that he is 'different enough' meaning that his ethnic origin is obvious and thus he would rather avoid disclosing chronic illness so as not to disadvantage himself further, as was the case in the past. Arguably, a tension between the majority or the native population and the migrants or newcomers is always evident (cf. Duda-Mikulin, 2019). Alex desires to be like everyone else'. The views of others, the majority, White people, are paramount:

It's not even the infrastructure, legislation and everything. It's just, I don't know, they would just judge me differently. They would just see me as, differently, as some kind of weakness.

Alex's illness perception translates into not wanting to be seen through the lens of illness. And whilst he is aware of the fact that there are policies in place that protect the rights of people with disabilities, he prefers not to bring attention to his condition. His fear of othering is quite striking:

I don't want to have a seizure in front of people or anything like this because just, what will they think, and then because our work is quite clinical as well, it's very technical as well, you need to be switched on. So, sometimes, it takes me longer to get things than the average person perhaps, and that might be to do with the structural and the parts of the brain that might have been affected. And then I don't want people to think I'm thick or something like this. I will work hard on it, and they might get things much quicker than me, some things, they won't.

Alex demonstrates internalised stigma and prejudice towards his disability (cf. Scambler, 1998). He is afraid of it as he experienced it in the past, but he shares the view that disability is something to be ashamed of. For him, disability equals weakness, hence the effort to hide the condition, especially since he has no such option with regard to ethnic origin. Coping and strategic action are key processes in responding to and presenting illness or a chronic condition. Alex could be described as using 'active-denial' as opposed to 'accommodation' in Bury's terms (1991) as he does not disclose his illness, not even to his closest family and he never 'came out' as disabled at work either. Non-disclosure of epilepsy is a coping mechanism designed to protect him against potential discrimination (through ableism and racism) and being re-marked as different. The change that matters is not in policies but in people's attitudes:

Respondent: 'Yes, it's not something I talk about much as well.

Interviewer: That's why I appreciate it very much.

R: It's locked away in the back of my mind somewhere. It's in a box.

I: But then it's interesting how you came forward. You put yourself forward to talk about it because it was your choice, wasn't it?

R: Yes, yes, because you said it was anonymous and things like that. And that's my wife as well, and I even said to her I'm going to back out, and she said, "Don't be stupid, why."

I: It's up to you, yes.

R: No, no, no, she was like, just because of that same reason why I didn't go to my reunion because sometimes, when you talk about it, you think about it, don't you. And sometimes, when something is locked away so deep, you don't want to bring it up.

I: Well, maybe it's healthy to talk to a stranger about stuff like that.

R: Yes, no, no, it is. I feel better for saying it.

His coping with limitations is similar to coping with poverty, family neglect, etc. Alex expressed views that he is not interested in activities most people do (e.g. swimming, driving, etc.) because he does not want to disclose the real reasons (i.e. it is dangerous for someone with epilepsy). Learning to drive could be seen as a rite of passage, and Alex seems to feel resentment at this lost opportunity and the fact that he had to wait to learn to drive, as it was deemed unsafe earlier when his peers were engaged in this. Alex feels underachievement despite high educational qualifications. He has very high expectations of himself, which may be a way to redraw the relative disadvantage linked to his illness or a way to prove to his extended family (and himself?) that he is not the incapable child they worried he was. The ethnicity is evident and inevitable, whereas his disability can be concealed as it does not match Alex's self-image.

Disclosure of disability could lead to exclusion, which, in consequence, could take away what he worked for. This includes the image of himself, which he created and works very hard to keep up. It is the image of a very capable, professional, smartly dressed white-collar worker who takes pride in his appearance. This is another coping mechanism to reconcile with his ethnic minority identity, which he again tries very hard to redress and show himself in a different light, not in line with common negative stereotypes. Arguably, all those efforts to hide certain elements of his identity and expose others signify Alex's very involved logical rational decision-making in the effort to create the identity that matches his internal image of himself. Here, we can see the interplay of agency and structure and the way they are intertwined in the life of this one British Pakistani man who has a diagnosis of epilepsy but makes every effort to present himself as a non-disabled and non-racialised person.

Hall's (1990) theorising around the relational nature of identity is particularly useful in explaining how Alex navigates this terrain. Hall describes identity as a structured representation, suggesting that it is not something inherent or fixed but something that is shaped by the interplay of various social, historical, and cultural forces. He emphasises that identity is not formed in isolation and that we come to understand who we are only when we encounter others who are different from us, which challenges the idea that identities can be defined independently of social relationships. Through this process of encounter and difference, our sense of self is defined.

Alex's perceived fear of ableism, stereotyping, othering and stigma related to the concept of disability on the one hand and wanting to fit in and longing for normality on the other, are among his motivations for non-disclosure of his illness: 'We were trying to fit into, they call it hybrid identity or something, and we were trying to be a bit of this and a bit of that and mishmash. We could be neither ...'.

He refers to 'difference' as something very negative and unwanted: 'being different is the worst'. This is linked with a desire to belong and be accepted as a member of a group (capable and successful professional white-collar workers) and the fact that being perceived as different or other would likely result in being denied access to this group membership and thus he developed and uses certain techniques to avoid coming out as a disabled person at work or at home. This, on the other hand, gives him agentic powers whereby a lack of agency which often signifies people with disabilities is redrawn and

he, as a disabled person, is now given the option not to disclose which he chooses every time as opposed to when he was a child and did not have that choice.

Disability is often seen as a binary state: disabled vs non-disabled, while for Alex, this can fluctuate. In Alex's case, to claim adjustments which he does not need, he would have to face the stigma attached to disability, which he dreads, and thus non-disclosure seems a logical decision. This may be a way of avoiding negative outcomes rather than having a focus on positive goals, while legal requirements around reasonable adjustments are not necessary.

Hybrid identity and belonging

The concept of intersectionality has been criticised for being reliant on black women as the basis for its claims. This paper relieves this tension as we use intersectionality to explore the lived experiences of a British-Pakistani disabled man. Although the race-gender binary is at play here, we wish to focus on the intersections between ethnicity and disability as aspects important to Alex, which were demonstrated in the interview with him.

While we accept that intersectionality is useful in theorising about all subject positions as everyone is constituted by the interplay of gender, sexuality, class, ethnicity, etc.; we use it to navigate through an intersectional identity of one multiply marginalised individual who identifies as British male of Pakistani origin and who has a diagnosis of epilepsy. That said, we recognise that Alex is, in many ways, privileged (e.g. acquired social status through education and professional standing; has a stable, well-paid job and a supportive family); however, like in any case, various vectors of power are present to constitute a truly unique experience. Alex demonstrates how racial normativity influenced him as a child and how he resists being pushed to the margins due to being visibly different. The same can be said about his non-normative body or the lack of able-bodied privilege, which he experienced intensely in his childhood. Yet, today he passes as a privileged non-disabled professional of a South Asian background. Thus, although Alex can now choose when to expose these parts of his identity, his social positions may intersect in such a way as to disadvantage him (cf. Zack, 2005).

We also recognise the need to bring in an analysis of agentic powers of those with intersectional identities. Alex's case shows that people may be able to choose when to come out and disclose their identity, as not all are powerless in that regard. Whilst a black woman (the prime example often used to explain intersectionality and criticised for it) may not often be able to take advantage of the privilege afforded to black men, a dark-skinned Asian-looking (disabled) man may be exposed to marginalization through that what is seen and so decides to hide his disability so as not to face multiply disadvantage. Hall (1990), Gilroy (1993) and Grossberg (1996) argued for a more fluid, interconnected understanding of identity that recognises the complexity and ongoing nature of identity formation, rather than confining people to static categories. This perspective emphasises the importance of looking beyond these rigid borders (be it ethnic or concerning bodily difference) and considering how identities are shaped by global connections and interactions.

As Nash emphasises, intersectionality fails to recognise how privilege and oppression intersect. It is clear from Alex's account that they are constantly at play which was enabled

by his fluctuating health condition which now allows him to pass as non-disabled and through certain positive societal changes in regard to ethnic minorities which are now better understood whilst he no longer is one of very few ethnic minority representatives in his neighbourhood. Alex himself emphasises 'hybrid identity' as a concept that fits in well with his life. He acknowledged that he is already visibly different due to ethnicity and his family's migration history. As he postulated: 'ethnicity was enough to deal with' when choosing (not) to come out as a disabled person:

Growing up South Asian, it was hard enough where we grew up. (...) I was born here [UK]. So, that was hard, being one of only four non-white kids in the whole school. It's slightly different now, and then having epilepsy as well, and I had the tonic-clonic seizures.

The fact that belonging to an ethnic minority was enough of a burden, and he did not want to add a chronic condition to it, is quite significant. He is first a person from an ethnic minority background, and then a disabled person, while it can be argued that he would rather reject both labels and remain seen as just Alex, a person. The fluidity of identifying himself as belonging to one or the other is key and most interesting. He says: 'it depends on context'. Grossberg (1996) questions the usefulness of focusing too heavily on notions of identity and difference. He argues that the rigid categories of identity (like ethnicity, nationality, or culture) might not be the most useful or productive way to understand human experience. Instead of strictly defining people by these characteristics, he suggests that we should explore more fluid, dynamic, and innovative ways of understanding who people are and how they relate to one another.

Alex notes that he created a multicultural family as his wife originates from South America, and so they, as a family, divide their time between the UK and the countries where their families come from. This demonstrates that he is somewhat at ease with his own roots and also proud to be able to raise his own children in contact with their various cultural traditions. This relates to lots of differences to reconcile.

Racism and ableism may constitute a double disadvantage, and thus Alex may prefer not to come out as a disabled person, especially since he suffered racial abuse as a child and so now wishes to avoid emphasising his differences (cf. El-Lahib, 2015). That said, this is almost irrelevant here as Alex systematically and actively rejects his disability as 'ethnicity was enough to deal with'. Disabled people do not often possess much agency, and Alex seems to control his 'hybrid identities' whereby one is evident (ethnicity) and the other is hidden/invisible (disability), hence he has the option of rejecting it (now).

There has been (some) change in legislation, perception and understanding with regards to disability rights, which is very positive (but somewhat irrelevant for Alex), and at the same time, there have been socio-political changes which resulted in increased racially aggravated crimes (e.g. Trump, Brexit, COVID-19). Still, Alex does not seem confident in national and international laws and legislations and just prefers to play the role of a highly skilled professional whose children can take advantage of their parents' varied roots:

Yes, and I think a lot of it is to do with education as well. To inform, to educate about people's conditions and focusing on their ability, **because everybody, I believe, has got some kind of disability** [emphasis added]. They might not be good at Maths, might not grasp numbers very easily. So, I think everybody has got that, and we're all individuals, aren't we? We're not machines, everyone is different in their own unique way, and integrate with people. And I

think the best thing, our school was separated in a way and I was just on the margin of being sent to a special school, and I think the way we do is integrate and mainstream everybody in society and make those adjustments.

Alex does not want to be seen as one-dimensional should this be due to his ethnic background, migration history or chronic illness? If he had accepted an identity as disabled, he would have allowed the 'situational disability associated with seizures to become generalised to all aspects of their lives' (Rhodes et al., 2008b). Visible differences take away other dimensions of a person while he does not wish for others to have a clouded view of him as a full person who throughout his life had to negotiate various, more or less evident and troublesome parts of his identity:

Everybody's got the same values, everybody wants the same thing. Whatever you ask them, they want to live in a safe society, they want to play a part in that society, they want to contribute, they want to live safely and securely, everybody wants the same thing.

Gilroy (1993) may be useful in explaining transnational significance here, as he argues that rather than categorising people into narrow, fixed groups, we should focus on broader, transnational perspectives. He highlights the importance of recognising global networks and issues, which transcend traditional ethnic or national boundaries. In this view, ethnicity is not a static or fixed characteristic but a continuous process of identity construction that evolves, and we should focus on interconnectedness rather than separation, and look for ways to explain the world that are not confined by narrow ethnic or national identities.

Conclusion

Alex emphasises: 'we are all the same (...) we all want the same things' and that 'everybody has got some kind of disability'. However, at the same time, he feels that this standpoint is not socially accepted yet and thus he wishes not to expose his disability to the public but still postulates seeing a whole person and not just their characteristics or indeed differences. The presented case study demonstrates the interplay of agency and structure and the way they are intertwined in the life of this one British Pakistani man who was diagnosed with epilepsy but makes every effort to present himself as a non-disabled and non-racialised person.

This paper adds to debates started by Hussain (2005) and continued by Inckle (2015) and Parks (2021), while it also contributes to theorisations by Duda-Mikulín and Głowacka (2023), Duda-Mikulín et al. (2020), Burns (2019), Hughes (2017) and Pisani and Grech (2015). Intersectionality is widely acknowledged and has previously been analysed in relation to race/ethnicity/migrancy, less so in relation to disability, which is the case here (cf. Parks, 2021). Disability and migration have largely been separate as the two fields seldom work together (Burns, 2019; Duda-Mikulín et al., 2020; Hughes, 2017). The intersectionality of ethnicity and disability and racism, and ableism constitutes truly nuanced forms of othering and a 'hybrid identity' to which Alex makes references.

The paper contributes to contemporary debates about how South Asian men with a disability construct new forms of identity in Britain. A qualitative case study of a self-identifying British Pakistani man who has a diagnosis of epilepsy sought to understand how he formulated identity and employed his own practices in navigating belonging in relation to his ethnicity/migrant background on the one hand and his disability/chronic illness on

the other. This paper primarily contends that Alex leveraged his hybrid identities in representing himself and finding common ground: he maintained attachments to the UK alongside his minority identification and diverse cultural practices, though he rejected identification with the disabled community and emphasised his professional background and achievements instead. Thus, following Grossberg (1996), Gilroy (1993) and Hall (1990), we ought to recognise identities as fluid, evolving, and shaped by ongoing interactions with others. This standpoint challenges the traditional notion that identity can be neatly defined and instead suggests that identity is an ongoing process of negotiation and construction that continuously occurs.

This research is not without its limitations, and as it is based on one qualitative interview, though full of rich data, we wish there were more studies like it to learn from. Thus, these findings are more indicative than conclusive; nevertheless, valuable to migration and disability studies scholarship. We hope there will be more research concerning the concepts of disability and migration, and more specifically, voluntary rather than forced migration, as there are currently very few such endeavours.

Noteworthy is the importance of lived experience accounts and detailed qualitative insights. Whilst there is very little research that takes an intersectional approach to ethnicity/migration and disability/illness, there is, however, a growing body of literature around mental health and these intersections (Keating, 2015). Given the need for research that examines the relationship between ethnicity and disability, this paper presents useful insights for academic and practice-based researchers in the field.

Notes

1. We recognise that South Asians may not be recognised as a community and certainly not as a homogenous community, nevertheless we consciously chose to refer to this term since it was the phrase that the respondent chose to use.
2. We wish to acknowledge the fact that we do not engage with religion in this paper although it inevitably matters when it comes to understanding disability/chronic illness. That said, the respondent never mentioned religion himself and thus there is no mention of it.
3. Tonic-clonic seizure characterises with stiffening of the muscles, losing consciousness and so falling to the floor while often making a groan; a person may in the process bite their tongue/cheek and so the saliva may look bloody; then the arms and usually the legs jerk rapidly and the person may lose control of their bladder or bowel as the body relaxes. See more here: <https://www.epilepsy.com/what-is-epilepsy/seizure-types/tonic-clonic-seizures>
4. We acknowledge here that we recognise the diversity of Pakistan and its various parts but as the research participant did not draw on this during the interview, we chose not to focus on this in this paper.

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Ethics

The project received ethical approval from the Ethics Committee at the University of Bradford, UK, before the start of the fieldwork.

ORCID

Eva Duda-Mikulin  <http://orcid.org/0000-0002-4937-0040>

Marta Głowacka  <http://orcid.org/0000-0002-3641-4825>

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