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Research & Practice Notes

Challenges of researching racism in healthcare

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The unprecedented transnational protests following the killing of George Floyd highlighted the need to re-examine institutions that uphold various social injustices experienced by racialised minorities. Black Lives Matter protests thus created a serious reckoning with racism and facilitated global conversations. Against the backdrop of these protests, we evaluate our study of healthcare workers, exploring racialisation in Swedish healthcare including the design and implementation of an anti-racist initiative in healthcare education. We reflect on how the silencing of discussion around racism in Sweden led to difficulties in recruiting participants and the effect of the shift in public discourse following the Black Lives Matter uprising of 2020. The project was ultimately successful in recruitment and outreach to professional and regional authorities. However, this success is contrasted by the lack of structural change in embedding anti-racism as a core value in healthcare practice. We conclude by noting that conversations about anti-racism differ from implementing anti-racist practice in commissioning, evaluation, and service delivery.

Introduction

We evaluate our interview and intervention design study of racism in Swedish healthcare between 2016 and 2020. The study interviewed 58 healthcare workers of varying occupational and ethnic backgrounds to explore different aspects of racialisation in Swedish healthcare (Bradby et al. 2019). The project was successful in recruiting and interviewing a wide variety of healthcare staff but it faced many challenges. We reflect over the challenges of recruiting participants, despite our extensive research and outreach experience and good networks. The widespread discussion of racist injustices was important to the life of this project, facilitating not only participant recruitment, but also the project's subsequent engagement with media, public health institutions and professional organisations to discuss the findings and the implementation of the project's anti-racism initiatives. While the zeitgeist allowed interest in our study, meaningful policy change has not taken place.

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Background

The study was funded by the Swedish Research Council (2016/04078), hosted by Uppsala University and subject to ethical review (Uppsala Regional Ethical Review Board (2018/201)). The study captured a range of views on racism and racialisation in Swedish healthcare. We interviewed healthcare workers from a variety of occupational and healthcare contexts as well as ethnic backgrounds. The study also designed anti-racism interventions for implementation in various healthcare settings including educational settings (Bradby et al. 2023). As collaborators we had accumulated decades of research experience between us, with well-developed scholarly, professional and community networks to call upon. Between us we spoke English, Swedish, Hindi, Arabic and Swahili fluently, had all migrated to Sweden, at different life stages, with three of us racially minoritised. With these qualifications and experiences, we were taken aback when, despite identifying candidates and exchanging multiple messages and calls over an extended period of time, and offering great flexibility regarding location and timing, it nonetheless proved difficult to persuade people to be interviewed. Individual staff members and representatives of medical training and healthcare provision were reluctant to be interviewed or to collaborate with us in co-designing and implementing anti-racist initiatives, despite assurances of confidentiality. This was particularly the case for racially minoritised healthcare staff who expressed anxiety at the prospect of being interviewed. They felt that should it become known that they had spoken with us, they could be labelled troublemakers and their employment would be jeopardised. But since they told us that they had witnessed or experienced racism, and were themselves racially minoritised, their ultimate refusal to be interviewed was itself significant for our study on racism. In taboo or hard-to-research topics, the difficulty of accessing experience itself becomes data; we interpret refusals as evidence of the racism to which racially minoritised staff are subjected in Swedish healthcare. Furthermore, racially minoritised staff who did agree to be interviewed described their distress and emotional labour at experiencing racism from patients and colleagues, a lack of space to discuss racism and fear of repercussions of undertaking such discussion (Ahlberg et al. 2022). While it was mostly racially minoritised staff that refused to be interviewed, White staff were also difficult to recruit as they felt uncomfortable discussing racism, which was taboo in the work place. The refusals were particularly notable given that, after May 2020, in the wake of the widespread BLM protests, our recruitment difficulties lifted. George Floyd's death in the USA was, in some ways, distant from the day-to-day experience of healthcare staff in Sweden. However, the shift it brought to our project's trajectory is worth considering.

Swedish Context

National identity in Sweden is often framed through claims of exceptionalism (Jansson 2018), centred on egalitarianism – a just society committed to human rights (Bäärnhielm et al. 2005) and gender equality. In the absence of a postcolonial public discourse or a civil rights movement, meaningful discussion of racism becomes difficult (Alinia 2020), not least due to the removal of the term 'race' ('ras' in Swedish) from statutes in 1973, on the grounds that the majority of the population was already anti-racist (Mulinari & Neergaard 2017). Swedish official and public discourse tend to declare Sweden a 'post-racial society' (since it is perceived to have transcended racism, any accounts of racism are viewed as individual experiences rather than a structural phenomenon), thereby disregarding Sweden's history of racialisation, colonial complicity and evidence of current racialisation in various institutions. Research into the role of racism in creating inequalities has been lacking in Sweden, although socioeconomic class and gender inequalities in income, education and health are noted in research (Bihagen & Härkönen 2016, Cavelaars et al. 2000, Mackenbach et al. 2016) and policy (Lundberg 2020). The role of racism in healthcare has been largely neglected, with greater attention paid to cross-cultural interactions (Milberg et al. 2016), othering (Torres et al. 2016) and diversity (Bäärnhielm et al. 2005) where an assimilation policy of

migrants is the goal. Sweden projects itself as the epitome of a modern welfare state (Thakur et al. 2003), with governance and access to health and welfare resources shaped by a commitment to scientific rationalism. Within this framework, race is presumed to belong to an outdated past – superseded by modernity and rendered obsolete and irrelevant by scientific progress. As healthcare practice draws on bioscience, racist discrimination is routinely unrecognized and obfuscated (Hamed et al. 2024). Our project has shown that racialized talk in healthcare routinely constructs racially minoritised users as uncivilized and hence their health symptoms, and especially pain, as less worthy of care (Hamed 2022).

With gender equality a key value in Swedish exceptionalism, employers are statutorily required to work towards equality of opportunities, which does not require racialised inequity to be addressed. Racially minoritised healthcare staff reported that their complaints about racism were dismissed on the grounds that 'we have an equal opportunities plan'. If institutions were working with equality, it was thus implied that racism was an impossibility. We also witnessed this dismissal when senior White clinical academics told us that junior colleagues' complaints of racism were baseless given the existence of an institutional equal opportunity plan (Hamed 2022).

When making contact with healthcare organizations, at the outset of this project, the lack of statutory recognition of racialization led us to fall back on the official category of 'migrant background', which in Sweden refers to being a migrant oneself or having at least one parent or another forebear who migrated. 'Migrant background' is used as a euphemism for racially minoritised status, since it rarely applies to White migrants. The longstanding political emphasis on successful integration of migrants, meant that some organizational gatekeepers viewed any research naming racism as provocative, divisive and highly undesirable. As the project progressed, our terminology developed, including ethnic and racialised minority/majority[1] and now White. The change in terminology developed in writing up the study.

Recruitment

Regardless of the terminology, we had limited success in identifying healthcare organizations that were prepared to cooperate and individual healthcare workers were reluctant to get involved. The unwillingness, fear and anxiety expressed by potential participants were unexpected. Previous research experience did not prepare us for this level of reluctance. The project's recruitment phase stretched from 2017 to 2020, partly because of the difficulty of securing participation. During that time, twelve racially minoritised healthcare professionals (including seven nursing assistants, one nurse-midwife, two pharmacists, one dentist and a primary care physician) refused to be interviewed, after initially expressing interest. These twelve potential participants had noted racism in their workplace, but despite being approached through known contacts and being assured of confidentiality, expressed anxiety about the consequences of being seen to engage in a discussion about racism. More specifically, they feared losing their current job. One nurse-midwife, insisted on meeting up far from her work place, to avoid being spotted by her colleagues in conversation with a racially minoritised researcher. These fears were not assuaged by our careful description of procedures to ensure interviewees' confidentiality and anonymity. As these 12 workers were not interviewed, and did not consent to their stories being shared, we cannot discuss their experiences and views on racism in detail, beyond stating that they experienced racism in

[1] We used the term racialised to describe the historical process by which certain groups are constructed as inferior through ongoing systems of oppression while the dominant group defines itself as superior and maintains structures that exclude the inferiorised group from power and resources. The terms minority or minoritised refer to people who are racialised as inferior and subject to differential treatment and unequal access to power and resources and are also minoritised in terms of power. White refers to the dominant group in Sweden. Sweden does officialy use racial categories, While Sweden does not officially use racial categories, the society is constructed by Whiteness and White privilege, often masked behind a colourblind and post-racial discourse.

their workplace. Most of the recruitment difficulties involved racially minoritised staff, but some White staff were also reluctant to engage with us for fear of saying the wrong thing: for instance, ahead of a focus group, a nurse anxiously joked with her manager: 'have you put me forward for this because you think I'm a racist?'

Recruitment was initially slow due to difficulties convincing people to participate. However, the summer of 2020 saw racism being more regularly discussed across diverse media platforms. Public debates, including evidence of racial inequalities exacerbated by the COVID-19 pandemic, gained significant traction in both legacy and new media. This represented a unique moment in Sweden where racialised injustice - usually dismissed - was brought into mainstream conversation. The visibility of these discussions challenged Sweden's self-image as an egalitarian society, prompting reflections on structural discrimination within its institutions. Recruitment to the study became easier with racially minoritised staff apparently feeling emboldened to express their own experience of discrimination and exclusion at work and eventually we spoke with 58 healthcare workers in one-to-one, paired and group interviews. The majority (36) of the workers interviewed were White, with only 22 racially minoritised participants, which limited the range of stories we were able to collect.

Outreach

Our aim was not only to analyse how racism plays out, but also to develop anti-racist educational materials for healthcare training programs. Drawing on interview evidence of racism in healthcare, we put together vignettes accompanied by reflective questions for trainee healthcare professionals (Bradby et al. 2023), and made the educational material freely available (Bradby 2022). However, we struggled to identify clinical training programs willing to implement this intervention. After several stalled negotiations, one author's ongoing collaboration with colleagues at the nursing programme at Jönköping University created the opportunity to co-design and implement a compulsory anti-racist educational intervention. The intervention was co-designed with colleagues working at the Department of Nursing, School of Health and Welfare at Jönköping University and comprised an online lecture on racism in healthcare focusing on the Swedish context, followed by a series of seminars with nursing students from various racialised backgrounds to discuss three case studies based on our interview material (Odzakovic et al. 2023). Racially minoritised nursing students described their own experiences of racism from healthcare users and colleagues as well as racism against racially minoritised healthcare users that they had witnessed. While it is difficult to evaluate whether or not the intervention resulted in actual change in students' way of thinking about racism as we did not conduct a longitudinal study, we noted that racially minoritised students expressed a feeling of relief as they were able to discuss racism. Students reflected on the embeddedness of racism in healthcare organization and on their own racialised behaviour. This intervention has been repeated in other healthcare training programs, including dental hygienists at Jönköping University in collaboration with Umeå University, graduate nursing students at the University of North Carolina in collaboration with Jönköping University (Odzakovic et al. 2025) and an undergraduate speech therapy programme at Uppsala University. In each case, the intervention has been repeated with more than three cohorts of students. The success of these educational programmes and the positive feedback we received from students show the need for anti-racist intervention education in healthcare training programmes. The challenge in implementing these programmes arose not from students' views but rather from institutional reluctance.

The widespread nature of debates on racism in 2020 also created interest in our project findings across a range of actors in public health and the National Board of Health and Welfare (Socialstyrelsen). (See https://www.uu.se/en/contact-and-organisation/staff?query=N12-1722 for a list of presentations, lectures and media contact). Discussing racism in healthcare remains a contested issue and debates have not resulted in any policy changes. The Black Lives Matter protests facilitated racially minoritised staff describing their experience of racism, which in turn led to the Swedish Social Minister at that time to

state that, although a discussion of the issue of racism was warranted, there was no need for a policy change, since laws against discrimination already exist (Heyman 2021). While the National Board of Health and Welfare recently published educational material to combat racism aimed at healthcare staff (Socialstyrelsen (The National Board of Health and Welfare) 2023), it failed to generate any anti-racist national guidelines or recommendations. Hence, it remains to be seen whether these debates will eventually generate any meaningful changes in the way racism is discussed in Swedish healthcare.

From mid-2020, we were regularly contacted by various media for commentary on racism in healthcare, particularly associated with two cases: a man, who later died, was refused an ambulance and his symptoms dismissed as 'cultural fainting' (kulturell svimning)[2]; journalistic investigations established that patients can request consultations with 'ethnically Swedish clinicians'[3]. In the current anti-migrant political climate, we do not receive media requests for commentary on instances of racism.

Conclusion

We suggest that the transnational protests against racialised injustice in 2020 were significant in shaping the interest shown in our project by individual interviewees and by public health institutions and media organisations. These protests created a context which enabled an anti-racist educational intervention, in which students affirmed their experience of racism as both an everyday reality in healthcare and an organisational problem. While there is some worth in re-stating the role of racism, without sustainable change embedded into healthcare organization, racialised harms will persist, particularly as discussion of racism once again becomes highly contested.

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